

Helping Children who Need Palliative Care to Access Education

A resource for schools,
colleges and early
years providers



Helping Children with Palliative Care Needs to Access Education: A resource for schools, colleges and early years providers

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Together for Short Lives is the leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them – families, professionals, and services, including children’s hospices. Our work helps to ensure that children can get the best possible care, wherever and whenever they need it. When children are unlikely to reach adulthood, we aim to make a lifetime of difference to them and their families.

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Principles

Four key actions for schools

Engaging and working collaboratively with children and their families

Engaging and working collaboratively with other professionals and organisations

Planning and implementing provision

Support and training for the school community

Useful resources

Introduction



What is a life-limiting/life-shortening condition?

Life-limiting conditions, sometimes known as life-shortening conditions, are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration, rendering the child increasingly dependent on parents and carers.

What is a life-threatening condition?

Life-threatening conditions are those for which curative treatment may be possible but can fail, such as children with cancer. Children in long-term remission or following successful curative treatment are not included.

How many children in the UK have life-limiting and life-threatening conditions?

It is estimated that there are at least 49,000 children under the age of 19, across the UK, living with a life-limiting or life-threatening condition and who may require palliative care¹. There are over 300 conditions which are life-limiting or life-threatening. In many cases, schools will be closely involved in the lives of children with such conditions and with their families.

Categories of life-limiting and life-threatening conditions

Some life-limiting conditions in children may be obvious at birth, whereas others gradually develop over time, or are degenerative. Many children suffer from multiple and complex illnesses and most have additional learning difficulties associated with their syndromes.

It is common for children and young people's conditions to fluctuate and, as such, it is often much more difficult to identify when they are moving into their end of life phase. Due to the variety and complexity of conditions, each child's prognosis, treatment and support needs will be unique.

Together for Short Lives recognises four broad groups of life-threatening and life-limiting conditions. Categorising them is not easy and the examples used are not exclusive. Diagnosis is only part of the process; the spectrum of disease, severity of disease and subsequent complications as well as the needs of, and impact on the child and family need to be taken into account.

Category 1	<p>Life-threatening conditions for which curative treatment may be feasible, but can fail. There may be periods of remission or acute crisis.</p> <p>Examples: cancer, irreversible organ failures of heart, liver, kidney.</p>
Category 2	<p>Conditions where premature death is inevitable. There may be long periods of intensive treatment, aimed at prolonging life and allowing participation in normal activities.</p> <p>Examples: Cystic Fibrosis, Duchenne Muscular Dystrophy.</p>
Category 3	<p>Progressive conditions without curative treatment options. Palliative treatment may extend over many years.</p> <p>Examples: Batten Disease and Mucopolysaccharidoses.</p>
Category 4	<p>Irreversible, but non-progressive conditions, causing severe disability leading to susceptibility to health complications and likelihood of premature death.</p> <p>Examples: severe Cerebral Palsy, multiple disabilities such as those following brain or spinal cord injury.</p>

1. Fraser L K, Parslow RC, McKinney PA, Miller M, Aldridge J M, Hain R and Norman P (2012). *Life-limiting and Life-threatening Conditions in Children and Young People in the United Kingdom*; Final Report for Together for Short Lives: Paediatric Epidemiology Unit, Leeds University. Available to download from: <http://bit.ly/1yvEeHs>.

What is children’s palliative care?

Palliative care for children with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

Whereas the majority of adults only need palliative care at the end of their lives, children and young people with life-limiting conditions require palliative care over a much longer period.



What could this mean for schools?

Child Bereavement UK has published an information sheet entitled *Children at School with a Life Limiting or Life Threatening Illness*². It states “schools and the resources at their disposal vary enormously. All are under pressure to meet targets and cope with constant change. A child with a life-limiting or life-threatening condition will add to this. However, with sensitive support, timely explanation, and most of all practical help, the majority of schools will respond with compassion and humanity. Indeed, many will go far beyond what is being asked.”

Child Bereavement UK also notes that “school is about so much more than just an education, it is also a place where children and young people make friends, learn about life and hopefully feel valued as an individual.”²

Schools can come into contact with children with life-limiting conditions from any of the four categories. Schools will be involved to a greater or lesser extent depending on:

- the nature of the child’s condition
- the way in which it develops
- the treatment that the child needs and the impact it has on them

The way in which a school engages with a child who needs palliative care can be categorised in the following way:

	The child maintains a steady level of engagement with the school with successful medical management and appropriate actions by school.
	The child’s engagement reduces over time as their condition deteriorates, requiring a flexible approach to planning and provision.
	The child’s engagement with schools fluctuates widely in relation to periods of treatment and remission. Periods of absence and re-admission will require regular revision of plans.
	Initially the child is engaged with school but a significant event leads to a sudden disengagement. This may require sensitive management of the school community.
	The child’s engagement with school increases over time as their treatment has a positive impact, requiring a flexible approach to planning and provision and high aspiration.

Principles of good practice: The 2014 context

The following published resources set out the principles which schools should adopt in enabling children with life-limiting conditions to access education:

The Children and Families Act 2014³

Section 19 of this act makes clear that local authorities, in carrying out their functions under the Act in relation to disabled children and young people and those with special educational needs (SEN), **must** have regard to:

- the views, wishes and feelings of the child or young person, and the child's parents
- the importance of the child or young person, and the child's parents, participating as fully as possible in decisions, and being provided with the information and support necessary to enable participation in those decisions
- the need to support the child or young person, and the child's parents, in order to facilitate the development of the child or young person and to help them achieve the best possible educational and other outcomes

The SEND Code of Practice 2014⁴

Many, though not all children with life-limiting or life-threatening conditions will fall within the definition of Special Educational Needs. In the *Special Educational Needs and Disabilities Code of Practice, 2014*, the principles of the Children and Families Act 2014 are further explained as being designed to support:

- the participation of children, their parents and young people in decision-making
- the early identification of children and young people's needs and early intervention to support them
- greater choice and control for young people and parents over support
- collaboration between education, health and social care services to provide support
- high quality provision to meet the needs of children and young people with SEN
- a focus on inclusive practice and removing barriers to learning
- successful preparation for adulthood, including independent living and employment

The Equality Act 2010⁵

The Children and Families Act 2014 references The Equality Act 2010 – which provides a single, consolidated source of discrimination law. Many children with life-limiting and life-threatening conditions will fall within the definition of disability (see Appendix 5B) which is covered by the Equality Act.

The Act makes it unlawful for the responsible body of a school to discriminate against, harass or victimise a pupil or potential pupil:

- in relation to admissions
- in the way it provides education for pupils
- in the way it provides pupils access to any benefit, facility or service
- by excluding a pupil or subjecting them to any other detriment

The overriding principle of equality legislation is generally one of equal treatment. A person must not discriminate and harass another on the basis of certain personal characteristics, including gender, ethnicity or disability. However, the provisions relating to disability discrimination are different in that you may, and often must, treat a disabled person more favourably than a person who is not disabled and may have to make changes to your practices to ensure, as far as is reasonably possible, that a disabled person can benefit from what you offer to the same extent that a person without that disability can. So in a school setting the general principle is that you have to treat people equally, regardless of their gender, ethnic background, faith or sexuality – but you may be required to treat disabled pupils differently (see Appendix 5A for further guidance).

3. Great Britain. The Children and Families Act 2014. Elizabeth II. Available to download from: <http://bit.ly/1wuOK1E>.

4. Department for Education (2014): *Special Educational Needs and Disability Code of Practice: 0 to 25 years: Statutory guidance for organisations who work with and support children and young people with special educational needs and disabilities: July 2014*. Available to download from: <http://bit.ly/1ri6Nkm>.

5. Great Britain. The Equality Act 2010. Elizabeth II. Available to download from: <http://bit.ly/1D2UJ0g>.

Both the *SEND Code of Practice and the Guidance on Supporting Pupils at School with Medical Conditions* draw their statutory powers from the Children and Families Act 2014. Throughout the development of the legislation and these guidance documents, the Government stressed the importance of the culture which lay behind the legislation and which they wished to permeate it.

The 16 principles of good practice which lie behind the Together for Short Lives *Core Care Pathway* embody a very similar culture – the centrality of the wishes of the family and child, the need to secure the best interests of the child, a commitment to collaborative, multi-agency working, an awareness of and empathy with spiritual and cultural wishes and a commitment to open, clear and mutually respectful communication. In this spirit, we would recommend that the reader uses this guidance in conjunction with the more general:

- *Supporting Pupils at School With Medical Conditions*⁶
- *Code of Practice for Children with SEN and Disabilities*⁴
- *Early Years: Guide to the 0 to 25 SEND code of practice*⁷
- *The Equality Act 2010 and Schools; Departmental advice for school leaders, school staff, governing bodies and local authorities*⁵

The Together for Short Lives Core Care Pathway

Together for Short Lives has developed a *Core Care Pathway*⁸. This is a tool for professionals who support children with life-limiting and life-threatening conditions and their families throughout their care journey, from diagnosis through to end of life care and bereavement support. It provides a clear framework for all practitioners and aims to facilitate a care process, supported by good communication between professionals across all care settings and families. It also places the child and family at the centre of the planning process; providing practical guidance at key stages of a child's care journey. The *Core Care Pathway* provides a process which is relevant to any condition as it focuses on the child's needs rather than the disease trajectory.



The principles which underpin the Together for Short Lives *Core Care Pathway* are:

- Best interest.
- Diversity and cultural issues.
- Consent, confidentiality and capacity.
- Communication.
- Uncertainty and losses.
- A unique bereavement journey for every child and family.
- Emotional and psychological support.
- Spiritual support.
- Multiple admissions.
- Co-ordinated care.
- 24 hour support.
- Ability to respond quickly and flexibly.
- Parallel planning.
- Advance Care Plan.
- Care for the team around the child.
- Risk assessment.

6. Department for Education (2014). *Supporting Pupils at School with Medical Conditions*. Available to download from: <http://bit.ly/1ug0fn7>.

7. Department for Education (2014). *SEND: Guide for early years settings*. Available to download from: <http://bit.ly/WG4pKL>.

8. Widdas D, McNamara K, Edwards F (2013). *A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions 3rd Edition*, Together for Short Lives, February 2013. Available to download from: <http://bit.ly/1yyeuoT>.

Principles

Principles of good practice

Principles of good practice



Child and family centred

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Principles of good practice

Principles of good practice



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What is it most important to get right?



Playing a full and active role in school life

Every child is entitled to play a full and active role in school life and clearly this includes children with life-limiting or life-threatening conditions. Schools “should ensure that such children can access and enjoy the same opportunities at school as any other child.”¹ This includes access to the building, the curriculum, lunch and break times, after school activities, trips and residential. It is not acceptable to deny children with life-limiting or life-threatening conditions access to this full range of activities simply because of transport difficulties or limitations on support and care.

Although schools operate in a world where health and safety concerns can dominate thinking, the challenge is to create the context in which the child’s engagement is not unfairly limited. Careful planning and risk assessment which reflect the priorities of the child and their family are tools which should be used to enhance opportunities rather than restrict them.

For a significant number of children and young people with such conditions the role of schools in providing a ‘normal’ life is paramount. Schools can be vital in providing social stimulation and a reason to get out of bed in the morning.

“For children and young people maintaining school attendance can be crucial to their overall well-being, especially when survival to adulthood is unlikely. School offers normality and a chance to be just like everyone else. It is a welcome refuge from the world of hospitals and illness.”

Children at School with a Life Limiting or Life Threatening Illness

“School trips and after school clubs are areas that children with complex needs can miss out on as the venues or activities chosen again aren’t always appropriate, but sometimes with a little more thought and planning these can be adapted to be inclusive of children with complex needs.”

Nurse for children with disability

“15 year olds shouldn’t have an adult around all the time. They need to be given the chance to be a normal teenager, including being able to do something wrong!”

Hospice Manager

“I took B to school from the hospice and was horrified to watch him disappear down a corridor, away from all the other children, accompanied by a support worker.”

Hospice Manager

“Often I hear stories from carers or parents that the complex needs child is taken to the sensory room if an activity isn’t deemed appropriate for them. This can lead to the child spending lots of time in the sensory room!”

Nurse for children with disability

“Children and young people with life-limiting and life-threatening conditions are often absent from school which makes it difficult for them to make and build relationships with their peers and staff at school. They get left out of the planning of school activities. When they are included, there are the additional problems related to their conditions including having the staff willing and able to meet their care needs, administer medication, keep them safe – especially out of school hours. This leads to this group of children often being excluded from school trips and activities.”

Hospice Manager

1. Department for Education (2014). *Supporting Pupils at School with Medical Conditions*. Available to download from: <http://bit.ly/1ug0fn7>.

“Concentrate on things that they are good at, enjoy and can achieve. Provide necessary support so that they can be members of the school council and any clubs they want to join. Make sure they are not being coerced to be the token disabled member of the team. Make sure they have a voice that is as strong as their contemporaries who are not disabled. Make sure they have fun, their kind of fun, not what the grown ups think they will find fun.”

Hospice Manager

“In order to create lasting memories for families, it is important for the child to have the opportunity to be involved in school life. This allows them to escape from medical issues, and sometimes over protective parents.”

Hospice Manager

“Be aware of who they like, as with everyone else they will have people they like to spend time with and those that they do not. Many in this group are unable to make choices about where they sit and who they sit/interact with.”

Hospice Manager

“The vast majority of children of primary school age with cancer do eventually return to primary school. In all, 82% of parents told us that their child had returned to school since their cancer diagnosis, and 60% of bereaved parents told us that their child had returned to school while receiving palliative care.”²

CLIC Sargent

Staying well and safe at school

“Parents of children with medical conditions are often concerned that their child’s health will deteriorate when they attend school. This is because pupils with long term and complex medical conditions may require ongoing support, medicines or care while at school to help them manage their condition and keep them well. Others may require monitoring and interventions in emergency circumstances. It is also the case that children’s health needs may change over time, in ways that cannot always be predicted, sometimes resulting in extended absences. It is therefore important that parents feel confident that schools will provide effective support for their child’s medical condition and that pupils feel safe. In making decisions about the support they provide, schools should establish relationships with relevant local health services to help them. It is crucial that schools receive and fully consider

advice from healthcare professionals and listen to and value the views of parents and pupils.”¹

When they first hear that a child with a life-limiting or life-threatening condition will be in their care, teachers and support staff may well feel anxious about what they could do wrong. This is a natural reaction to a responsibility which is outside their area of expertise. It is vital that schools access advice and training to enable staff to feel confident in this area. There is guidance available about a school’s role in administering medication and carrying out medical procedures, outlining those which school staff can perform (with appropriate training) and those which are limited to health professionals.⁴

“School staff may be anxious about taking on the responsibility of supporting a pupil with complex health needs. For this reason, identifying the pupils day-to-day care needs, and anticipating and managing potential risks are key factors to ensuring success.”

Children at School with a Life Limiting or Life Threatening Illness

“Children with cancer often have gaps in their education. This can be due to going into hospital, the side effects of treatment, or generally not feeling well enough to fully take part in daily school life. As (a) child’s health improves and if treatment allows, going back to school may be a relief or a challenge. For many children, school is a refuge from the world of hospitals and procedures - a place for fun, friends and learning and a sign that life is returning to normal. However, some children, especially teenagers, may dread going back to school. This may be because of temporary or permanent changes in their appearance. Or they may worry that they’ll have missed a lot of work, or that being away will have affected their relationships with their friends. Bullying may be an issue for some children.”³

Macmillan

2. CLIC Sargent. 2012. *No Child with Cancer Left Out – The impact of cancer on children’s primary school education*. Available to download from: <http://bit.ly/1B6yZPV>.

3. Macmillan. 2015. *Your Child’s Feelings when they have Cancer*. Available to download from: <http://bit.ly/151Dv4S>.

4. Royal College of Nursing (2012). *Managing Children with Health Care Needs: Delegation of clinical procedures, training, accountability and governance issues*. Available to download from: <http://bit.ly/1x9p6ur>.

“Intellectually A was an able young man who needed to be in a teaching set that matched his ability, but the impact of his condition masked his ability. A had difficulty recording his work due to poor muscle tone. Working memory was affected very quickly as was speech. Initially departments moved A into lower sets where the pace of work matched A’s performance but not his ability. This led to A becoming very frustrated and becoming de-motivated.”

SENCO

“One school I worked with allowed a sick child to take their duvet into the classroom, so that they could have a sleep in the ‘quiet corner’ if they felt tired during the day. This worked really well, as the other children in the class would work quietly whilst the child had a sleep. This kind of care was helpful in so many ways, as it allowed the child to dip in and out of school life, helping them to feel normal again, and also made the other children aware of the needs of others.”

Hospice Manager

“Flexibility is the biggest asset. The child may come into school for some sessions so that they can see their friends. They are often not bothered by ‘lessons’ in the final stages but they usually want to see their friends and are desperate for some normal life.”

Hospice Manager

“The planning for their education should always take into account periods of time when the child will be too ill to attend school.”

Hospice Manager

Achieving full potential as a learner and as a person

The uniqueness of every child and the views of the family should be paramount in this area. High expectations and provision of access to learning will be essential aspects of the planning process. Care should be taken to ensure that physical and/or communication difficulties do not limit a young person’s achievement.

For other children, academic achievement may be a lower priority. Social and emotional well being may rank much higher. The routine of attending school may be a major element of stability and ‘normality’ for the family. Schools are likely to be part of a package of support for the child and family, involving other services such as hospice care, Portage, Home and Hospital Teaching Service, therapists, social care and other medical specialists. It is important that schools are fully engaged in the planning process, understanding the purpose of the support and their role in delivering successful outcomes.

Schools “should try to ensure special considerations are given to the timetable. If the child is unlikely to complete full days, or weeks, in consultation with the school, the timetable will need to be adapted. To provide as rich an experience as possible for the child, the focus may not need to be on academic learning. Leaving a lesson early to attend to care needs may be preferable rather than missing out on social interaction at break times”.

Children at School with a Life Limiting or Life Threatening Illness

“In planning to meet his needs the number of GCSE passes and levels of progress had to be seen as secondary in importance. Uppermost in our minds had to be A’s emotional well-being; he needed intellectual stimulation and challenge without the worry of examinations, and to be amongst his peers. Moving into the sixth form was a way of maintaining these contacts but more importantly gave A a reason to get up each morning.”

SENCO

“We met frequently with Mum to review provision in light of his changing needs and as his condition progressed there were daily exchanges of information at the start and end of each day. As his condition worsened this daily exchange of information was vital as his physical abilities fluctuated so much. We had to know how steady or unsteady he was, if he had slept well or was over tired which impacted on his physical abilities and in particular his swallow reflex.”

SENCO

“Parents also feed back that they don’t feel that their children are reaching their full potential as sometimes the assumption is made that they don’t understand as they can’t communicate verbally.”

Nurse for children with disability

“Don’t assume that the young person will not reach adulthood. Advances in medicine and the unpredictability of some conditions mean that for many children plans should reflect ambitions and aspirations for life beyond school. ”

Hospice Manager

“It is important to ensure that full and up to date care plans are available and understood by all. Know them well enough to know when something is not right.”

Hospice Manager

“We worry about being responsible for significant health needs but our strong relationships with health professional is very helpful. Staff are able to express their concerns and ask questions which does a lot to allay their fears.”

Head of special school

“We had to learn to be really aware of the possible impact of other children’s everyday illnesses on H. His low immunity meant that it was vital that we knew about any childhood diseases in the school.”

SENCO

“As soon as A received a diagnosis a meeting was arranged with the specialist medical team. The information we were given at this time, although generic, was vital as it provided us with the initial knowledge we needed to start planning support for A.”

SENCO



The three stages



The *Core Care Pathway for Children with Life-limiting and Life-threatening Conditions*¹ sets out a broad outline of the key events or processes that happen during the journey made by children with life-limiting and life-threatening conditions and their families. Although this is shown as a linear process, children may move backwards and forwards between the different stages, or miss stages out in their journey, depending on individual circumstances. It is divided into three stages:

Stage one: Diagnosis or recognition

“The key is that the family is aware that their child has a life-limiting condition and sharing this news marks the first important milestone along the pathway. Some children will have a very short life expectancy and will move to the final stage of the pathway quickly, while others will have long term conditions that will require many years of support as set out in the middle phase.”

Together for Short Lives Core Care Pathway

For a school, this can be when a child is diagnosed with a life-limiting or life-threatening condition, or it may be when a child with such a condition is admitted to the school.

Stage two: Ongoing care

“Many children will live their whole life during this stage of the pathway. The reality is that the whole family is living with the uncertainty of a life-threatening condition. An approach of parallel planning where there is a plan for living life to the full, including accepting risks to enhance quality of life is most appropriate.

Throughout a child’s illness a wide variety of health, social services, education and voluntary agencies will become involved.

All children have a statutory right to education and this includes children with health conditions. Enabling school attendance for some will require support staff and highly complex planning while for others, physical needs may not be an issue.”

Together for Short Lives Core Care Pathway

In the school setting, this is the period of time in which the child is in a more or less stable condition, which allows access to some or all aspects of school-life.

Stage three: End of life

“Recognition of end of life is an important step within the care pathway and enables the families and professionals to focus and plan for the death of the child. Multi-agency care planning and joint working is fundamental to the care of the child at this stage.

Parallel planning can help families prepare for the future and can make it feel acceptable to hope for the best alongside preparing for the worst.”

Together for Short Lives Core Care Pathway

For a school, there will be key issues around support for family, peers and friends; decisions to be made about actions to take as the child is known to be approaching death, or if the child dies.



1. Together for Short Lives (2013). *A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions*. Available to download from: <http://bit.ly/18Vd3JV>.

Roles and responsibilities



The following passages are from the statutory guide – *Supporting Pupils at School with Medical Conditions: Statutory guidance for governing bodies of maintained schools and proprietors of academies in England*¹.

The governing body should ensure that the school's policy clearly identifies the roles and responsibilities of all those involved in the arrangements they make to support pupils at school with medical conditions.

Supporting a child with a medical condition during school hours is not the sole responsibility of one person. A school's ability to provide effective support will depend on working co-operatively with other agencies. Partnership working between school staff, healthcare professionals (and, where appropriate, social care professionals), local authorities, and parents and pupils will be critical. An essential requirement for any policy therefore will be to identify collaborative working arrangements between all those involved, showing how they will work in partnership to ensure that the needs of pupils with medical conditions are met effectively.

Some of the most important roles and responsibilities are listed below, but schools may additionally want to cover a wider range of people in their policy.

- **Governing bodies** – must make arrangements to support pupils with medical conditions in school, including making sure that a policy for supporting pupils with medical conditions in school is developed and implemented. They should ensure that pupils with medical conditions are supported to enable the fullest participation possible in all aspects of school life. Governing bodies should ensure that sufficient staff have received suitable training and are competent before they take on responsibility to support children with medical conditions. They should also ensure that any members of school staff who provide support to pupils with medical conditions are able to access information and other teaching support materials as needed.
- **Headteachers** – should ensure that their school's policy is developed and effectively implemented with partners. This includes ensuring that all staff are aware of the policy for supporting pupils with medical conditions and understand their role in its implementation. Headteachers should ensure that all staff who need to know are aware of the child's condition. They should also ensure that sufficient trained numbers of staff are available to implement the policy and deliver against all individual healthcare plans, including in contingency and emergency situations. This may involve recruiting a member of staff for this purpose. Headteachers have overall responsibility for the development of individual healthcare plans. They should also make sure that school staff are appropriately insured and are aware that they are insured to support pupils in this way. They should contact the school nursing service in the case of any child who has a medical condition that may require support at school, but who has not yet been brought to the attention of the school nurse.

- **Staff** – any member of staff may be asked to provide support to children with medical conditions, including the administering of medicines, although they cannot be required to do so. Although administering medicines is not part of teachers' professional duties, they should take into account the needs of children with medical conditions that they care for. Staff should receive sufficient and suitable training and achieve the necessary level of competency before they take on responsibility to support children with medical conditions. Any member of staff should know what to do and respond accordingly when they become aware that a child with a medical condition needs help.
- **School nurses** – every school (though not all other settings) has access to school nursing services. They are responsible for notifying the school when a child has been identified as having a medical condition which will require support in school. Wherever possible, they should do this before the child starts at the school. They would not usually have an extensive role in ensuring that schools are taking appropriate steps to support children with medical conditions, but may support staff on implementing a child's individual healthcare plan and provide advice and liaison, for example on training. School nurses can liaise with lead clinicians locally on appropriate support for the child and associated staff training needs – for example, there are good models of local specialist nursing teams offering training to local school staff, hosted by a local school. Community nursing teams will also be a valuable potential resource for a school seeking advice and support in relation to children with a medical condition.
- **Other healthcare professionals, including GPs and paediatricians** – should notify the school nurse when a child has been identified as having a medical condition that will require support at school. They may provide advice on developing healthcare plans. Specialist local health teams may be able to provide support in schools for children with particular conditions (eg asthma, diabetes, epilepsy).
- **Children** – those children with medical conditions will often be best placed to provide information about how their condition affects them. They should be fully involved in discussions about their medical support needs and contribute as much as possible to the development of, and comply with, their individual healthcare plan. Other children will often be sensitive to the needs of those with medical conditions.
- **Parents** – should provide the school with sufficient and up-to-date information about their child's medical needs. They may in some cases be the first to notify the school that their child has a medical condition. Parents are key partners and should be involved in the development and review of their child's individual healthcare plan, and may be involved in its drafting. They should carry out any action they have agreed to as part of its implementation, eg provide medicines and equipment and ensure they or another nominated adult are contactable at all times.



- **Local authorities** – are commissioners of school nurses for maintained schools and academies. Under Section 10 of the Children Act 2004, they have a duty to promote co-operation between relevant partners such as governing bodies of maintained schools, proprietors of academies, clinical commissioning groups and NHS England, with a view to improving the wellbeing of children with regard to their physical and mental health, and their education, training and recreation. Local authorities should provide support, advice and guidance, including suitable training for school staff, to ensure that the support specified within individual healthcare plans can be delivered effectively. Local authorities should work with schools to support children with medical conditions to attend full time. Where children would not receive a suitable education in a mainstream school because of their health needs, the local authority has a duty to make other arrangements. Statutory guidance for local authorities sets out that they should be ready to make arrangements under this duty when it is clear that a child will be away from school for 15 days or more (whether consecutive or cumulative across the school year).
- **Providers of health services** – should co-operate with schools that are supporting children with a medical condition, including appropriate communication, liaison with school nurses and other healthcare professionals such as specialist and children’s community nurses, as well as participating in locally developed outreach and training. Health services can provide valuable support, information, advice and guidance to schools, and their staff, to support children with medical conditions at school.
- **Clinical commissioning groups (CCGs)** – commission other healthcare professionals such as specialist nurses. They should ensure that commissioning is responsive to children’s needs, and that health services are able to co-operate with schools supporting children with medical conditions. They have a reciprocal duty to co-operate under Section 10 of the Children Act 2004 (as described for local authorities). Clinical commissioning groups should be responsive to local authorities and schools seeking to strengthen links between health services and schools, and consider how to encourage health services in providing support and advice (and can help with any potential issues or obstacles in relation to this). The local Health and Wellbeing Board will also provide a forum for local authorities and CCGs to consider with other partners, including locally elected representatives, how to strengthen links between education, health and care settings.
- **Ofsted** – their inspection framework places a clear emphasis on meeting the needs of disabled children and those with SEN and considering the quality of teaching and the progress made by these children. Inspectors are already briefed to consider the needs of children with chronic or long-term medical conditions alongside these groups and to report on how well their needs are being met. Schools are expected to have a policy dealing with medical needs and to be able to demonstrate that this is implemented effectively.



Unacceptable practice



The following passages are from the statutory guide *Supporting Pupils at School with Medical Conditions: Statutory guidance for governing bodies of maintained schools and proprietors of academies in England*¹.

This guidance refers only to schools, but offers a guide to good practice which will have value for any educational setting.

Governing bodies should ensure that the school's policy is explicit about what practice is not acceptable. Although school staff should use their discretion and judge each case on its merits with reference to the child's individual healthcare plan. Practice that it is not generally acceptable is listed below:

- Preventing children from easily accessing their inhalers and medication and administering their medication when and where necessary.
- Assuming that every child with the same condition requires the same treatment.
- Ignoring the views of the child or their parents; or ignoring medical evidence or opinion (although this may be challenged).
- Sending children with medical conditions home frequently or prevent them from staying for normal school activities, including lunch, unless this is specified in their individual healthcare plans.
- If the child becomes ill, sending them to the school office or medical room unaccompanied or with someone unsuitable.

- Penalising children for their attendance record if their absences are related to their medical condition, eg hospital appointments.
- Preventing pupils from drinking, eating or taking toilet or other breaks whenever they need to in order to manage their medical condition effectively.
- Requiring parents, or otherwise making them feel obliged, to attend school to administer medication or provide medical support to their child, including with toileting issues. No parent should have to give up working because the school is failing to support their child's medical needs.
- Preventing children from participating, or creating unnecessary barriers to children participating in any aspect of school life, including school trips, eg by requiring parents to accompany the child.



Engaging and working collaboratively with children and their families: Stage one



The context in which a school becomes aware of a child with a life-limiting condition can vary widely. It may receive a child with a well-established diagnosis, or need to manage a scenario where a child who is established in the school is diagnosed with a life-limiting or life-threatening condition. It is important to reflect on the particular context in which you find yourself. Consider, for instance:

- Are the parents and child knowledgeable about the condition and familiar with the demands which it makes of them?
- Are you sharing in the trauma of a diagnosis which has a shattering impact on the family, who are suddenly faced with the loss of their child?
- Is the family in a position to offer leadership and strength to the team around their child, or do they have a real need for support? At this point the school may find themselves acting as a compassionate ear or a source of signposting to support, including charitable organisations such as Contact a Family¹, REACT² or the Maypole Project³.

It will be important for the school to identify the aspirations of the family, including those of the child. School could be one of the most important places in the life of the child, due to their need for 'normalisation' in a changed world, or an academic challenge could be a significant motivational factor for the child. The school may also be a key contributor to the child's network for spiritual and emotional support – either because of the faith embodied in the school, or due to a close relationship with individual member(s) of staff. School should also consider the implications for siblings and close friends.

“This can be one of the hardest times, with families feeling scared, alone or isolated. They may be trying to get used to medicalised language, meeting new teams and dealing with feeling that their family privacy is being invaded.”

Together for Short Lives Core Care Pathway

Sharing and understanding the aspirations of the family and their child will be essential – what are you trying to achieve together? The school has a duty to find ways to offer the child access to the same opportunities which are enjoyed by all children, but this must be addressed with sensitivity. Remember, a family might find it deeply upsetting to enter into discussions about activities which are clearly beyond their child, or even are planned for a future beyond the expected life of their child. Others will want to adopt a ‘have a go’ attitude, hoping that there is an opportunity for their child to enjoy the planning and at least engage in some of the activities. All of this will involve the school in clear risk assessment strategies.

“When it was clear that my son had the condition I decided that he must have a life – we must have a life together. So, I took him home and we took risks. We went to the park, on a train ride, to Disneyland... He is still with me and has just started school... we’re making the most of our time together and we’re a family now.”

Parent

1. www.cafamily.org.uk

2. www.reactcharity.org

3. www.themaypoleproject.co.uk

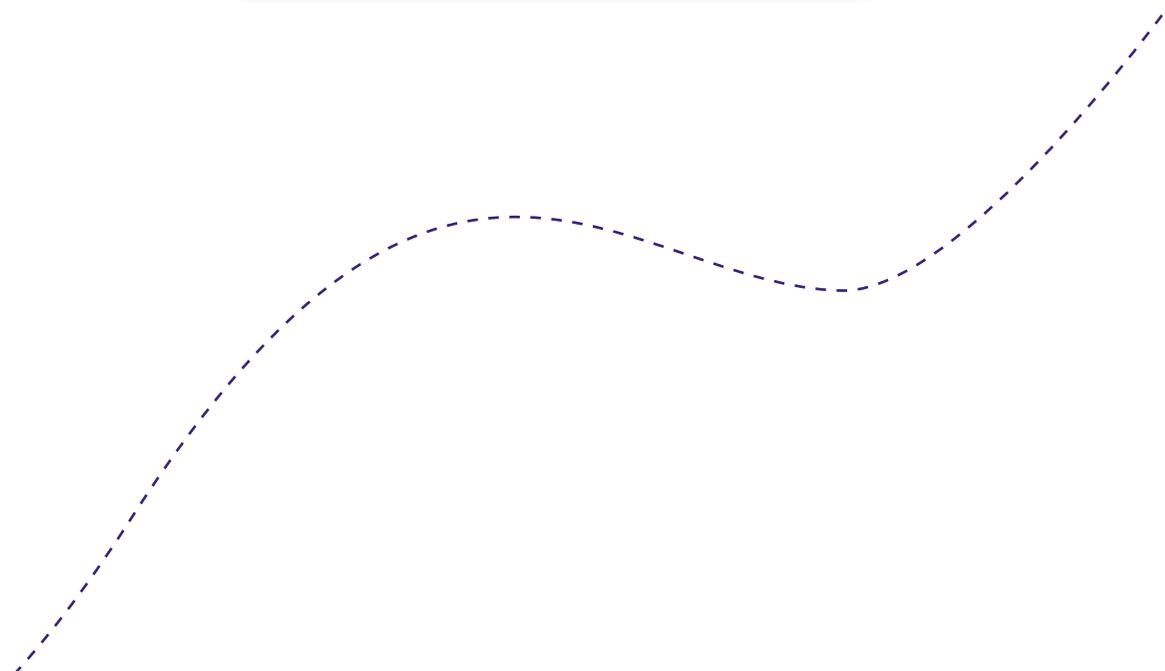
“At this time families need honesty, respect and, above all, time from professionals.”

Together for Short Lives Core Care Pathway

Parents will have strong views about what they want to be shared and what they prefer to remain confidential. You may need to have discussions around what you need to share in order to secure the child's safety and wellbeing in school. It may also be important to discuss how much information to share with the wider school community (classmates, close friends etc). Don't leave these matters in limbo – they are better addressed openly.

Questions to consider

- Have you considered the emotional position of the parents?
- What is the child's response to their condition?
- Have you listened to the aspirations, priorities and concerns of the parents and child?
- Are there implications for siblings, or close friends within the school?
- Have you discussed with the family who should be told what about the child's condition?
- Have you thought about the religious or cultural context?
- Are you aware of the organisations which may be able to offer support to the family?



Engaging and working collaboratively with children and their families: Stage two



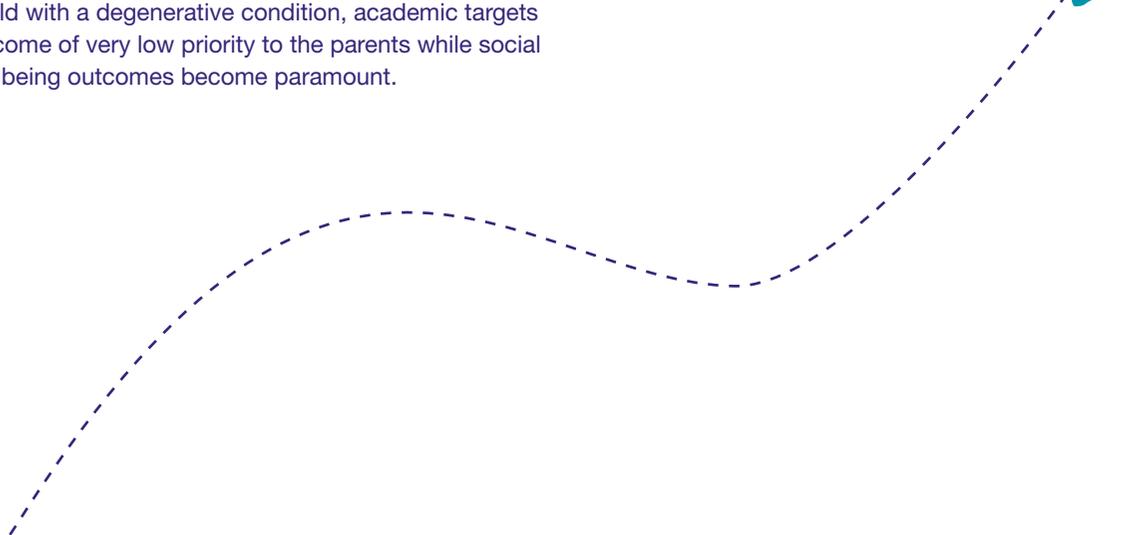
Throughout the planning and delivery of stage two, real parental engagement is critical, as is commitment to working in the best interests of the child. Communication is essential – clarity and honesty are paramount. Although ‘ongoing care’ may suggest a smooth, long term continuum of provision, this will by no means always be the case. A child with a life-limiting or life-threatening condition could indeed go through the whole school phase in which you work in a fairly stable condition. However, they could suffer from a progressive condition, which means that their time with you is set against a background of deteriorating health and narrowing capacity to engage alongside their peers. Or they could experience repeated episodes of treatment and hospitalisation, interspersed with periods of engagement with school. Any of these episodes could call for a review of planning and provision, against a backdrop of changed prognosis and capacity.

Have you considered the impact of these (and other) scenarios on the parents and child? Fluctuation and uncertainty are hard to live with and multiple admissions or re-admissions place fresh challenges before the child. These difficulties represent challenges, but they can also lead to depression, anger, rejection or unpredictability. The family’s priorities may change considerably over time. For example, for a child with a degenerative condition, academic targets may become of very low priority to the parents while social and wellbeing outcomes become paramount.

“For many families, the management of the child’s symptoms will be their prime consideration. For children whose symptoms are stable, other issues may be of greater importance. Most children will want to enjoy some kind of ‘normality’ with their peers, so school and leisure opportunities are an essential part of the assessment process.”

Together for Short Lives Core Care Pathway

How is the school able to contribute to the emotional or psychological support of the child, or peers and friends? You could find yourselves at the heart of a support network, perhaps needing to develop some new skills. The school will probably be working in partnership with a number of other agencies, perhaps called upon to co-ordinate its work as part of a 24 hour package.



Key working

Key working is one of the most important elements of support for children, young people and families – it helps them to live 'ordinary' lives and enables the growth of strong and resilient families. The overall aim of key working is to ensure the provision of holistic care and support to meet the individual requirements and aspirations of the child and their family. The care and support should be family-centred, not just child-centred. The individual offering key working support should strive for an open and supportive relationship with the child and their family, and this should be developed through regular and proactive contact.

Key working has developed from a role to a function so that key working becomes integral to everyone's role and all professionals and organisations supporting children and families are clear about what the key worker functions are. You can find more about this information in the report of the SEND pathfinder evaluation of key working and workforce development¹ – or from the Early Support Programme².

Questions to consider

- Do your plans clearly reflect the views and aspirations of the parents and child?
- Is the family fully involved in drawing up and reviewing plans?
- How is the child's voice regularly heard to inform provision?
- Are you responding flexibly and quickly to parental concerns or to changes in their aspirations and priorities as the medical situation changes?
- Do you respond to changes to the family's emotional, psychological and spiritual needs?
- Are you clear about your role in delivering key working functions?



1. Hill K, Craston N, Daff K and Thom G (2014). *Special Educational Needs and Disability Pathfinder Programme Evaluation Thematic Report: Key working and workforce development (pt 1) Research report*. Available to download at: <http://bit.ly/1zaJH4v>.

2. www.councilfordisabledchildren.org.uk/earlysupport.

Engaging and working collaboratively with children and their families: Stage three



Although it is not a common experience for schools to lose a pupil as a result of medical issues, there are approximately 49,000 children under the age of 19 living with a life-limiting or life-threatening condition in the UK. The end of life stage is clearly a very stressful and difficult time and one that requires particularly sensitive interaction with and support for families.

Issues of culture and diversity will be even more significant to many families at this time, so a conversation about the meaning of death and associated beliefs should not be put off. It is to be hoped that a relationship of honesty and trust has developed, though this cannot be assumed if the illness has been short.

The potential role of the school in emotional, psychological and spiritual support should be clarified. Some parents may be keen to come into school and talk to their child's peer group, whilst others may wish to withdraw while they grieve. The wishes of parents about school involvement in funeral and memorial events should be sought, so that school can arrange these matters without fear of causing further upset.

"This is likely to be a very difficult time for the family and it may be the point at which they are facing the reality of their child's death for the first time. It is important to recognise the family's need to have as much privacy as possible and that time with their child is very precious."

Together for Short Lives Core Care Pathway



Questions to consider

- Have you discussed with parents their wishes should their child suffer a critical deterioration or death whilst in school?
- Does the child have any special wishes, goals or ambitions they wish to achieve in their time in school?
- What would the family like you to tell the school community?
- How do the parents and child want you to maintain engagement while the child is in hospital or hospice?
- What are the family's wishes for commemoration?
- What are the family's wishes about representation at the funeral?
- Who is the most appropriate person in the school to liaise with the family both before and after the death of the child?
- Are there any siblings in the school, for whom you need to make particular arrangements?



Engaging and working collaboratively with other professionals and organisations: Stage one



To have a child diagnosed with a life-limiting or life-threatening condition is emotionally devastating for a family and will have a huge impact on their lives. The diagnosis also raises challenges for the team of professionals who become involved with the child and parents. They must ensure at all times that the interests of the child are paramount to their thinking, even though this may be difficult for individual professionals. The need to liaise with family and fellow professionals may not fit in with the school's normal working day, week or term, but the response must be driven by a flexible and child-focused approach. It may be that the diagnosis is made after a period of hospitalisation, or it may be followed by a long period of treatment which disrupts education, so the school will need to try to offer the best access to education that can be offered in the individual circumstance.

“School nurses are responsible for notifying the school when a child has been identified as having a medical condition which will require support in school. Wherever possible, they should do this before the child starts at the school. Community nursing teams will also be a valuable potential resource for a school seeking advice and support in relation to children with a medical condition.”

Supporting Pupils in School with Medical Conditions

“From the time of diagnosis, parents and professionals should recognise that they will be entering into a partnership of caring for the child.”

Together for Short Lives Core Care Pathway

Treating each child and their family as an individual, unique case and recognising that the importance of education to the family can fluctuate significantly may be the best attitude to adopt. It is highly likely that education will not be the ‘lead service’ in the child’s life at this time. The ‘tell it once’ approach can ensure that families do not have to repeatedly explain potentially very painful issues. Liaison with the lead professional (for example, the children’s community nurse or a specialist nurse) and co-ordination of responses will be helpful to parents. Parents may take on a key co-ordination role, or may struggle to do more than keep the family going. Sensitivity and flexibility will be key to your response. It may be that the school’s role is built into a 24 hour package of care, in which case your support will be crucial to the family’s ability to manage, not just with caring for their seriously ill child, but also coping with siblings, jobs and all the other components of family life which need to be maintained. It will be important for school to open links with medical specialists – community nursing team, specialist (condition focused) teams and local paediatricians. Your school nurse will be helpful in opening up these channels. The school should also forge links with local voluntary sector providers of children’s palliative care – including the local children’s hospice – which could be providing services to the child. For example, the child may continue to attend school while on a short break, or while staying at a children’s hospice for symptom management or step-down care.



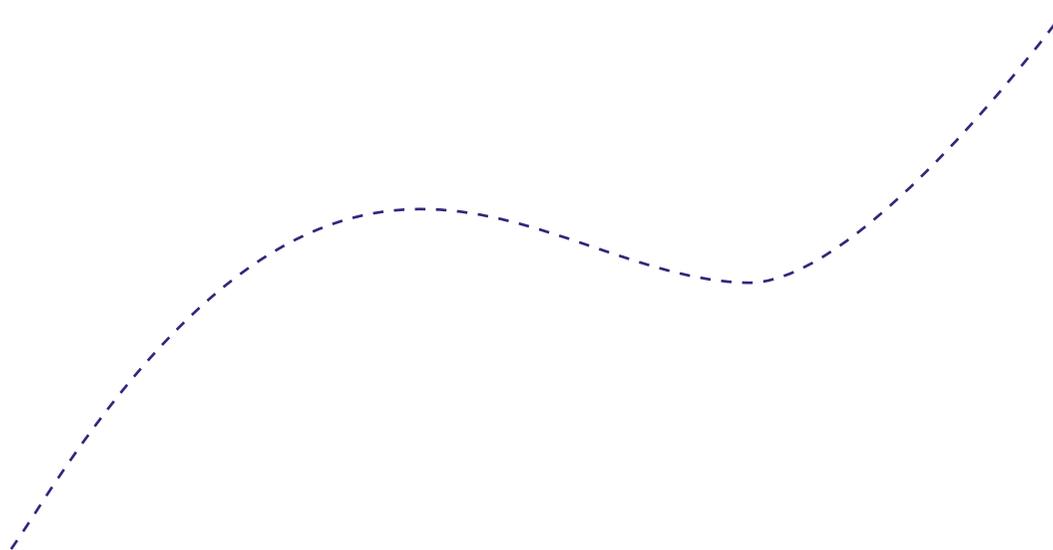
“We were really lucky with mum being very proactive – we worked with the nursery and medical staff before the school started to take on any roles. Before he came onto the school roll things were quite sorted.”

SENCO

There may already be a care plan in place, in which case the school will pick up some roles when the child is able to engage with education. Ensure that you continue to include the family in decision making. Think carefully before you embark on any condition related research. Be careful where you source information – Google will offer quick access, but it could set you on the wrong track. Better to seek input from the nursing team, if parents are happy, with support from specialist charities. Use the professionals in the team around the child to gain accurate information which is directly applicable to the child.

Questions to consider

- Have you involved your school nurse?
- Do you know who the lead professional is in the child's case?
- Have you established lines of communication with the health professionals and other agencies and gained the parents' consent to contact them directly?
- Are you bearing in mind the 'tell it once' approach?
- Are you continuing to involve the family at the heart of the multi agency team?
- Have you informed yourself about the child's condition in a reliable manner?



Engaging and working collaboratively with other professionals and organisations: Stage two



In this phase, you will find yourself working with a wide range of professionals from health and care services. You may find that a parent takes on a lead role in co-ordinating the team and sharing information, or one of the multi-agency team may take on key working responsibilities. The key principles of communication, confidentiality, flexibility and uniqueness will be crucial. It is in this stage that your flexibility may be challenged by the requirements of multiple admissions to hospital, for treatment or palliative care. This stage may last through the child's entire educational phase, or may be a period of months, before their deteriorating condition forces the move into the next phase of provision. Co-ordination of the school's efforts with those of other professionals will be crucial – at some times school will be central, but at others it may retreat to the margins. You may be working in close collaboration with the Home and Hospital Teaching Service. Team working will be essential – it is unlikely that you will be asked to adopt the lead professional role, but not impossible.

“Throughout a child's illness a wide variety of health, social services, education and voluntary agencies will become involved. Key working principles involve one agency taking a lead role, developing a crucial element of partnership working with the child and family, enabling them to take control of their situation and identify their needs. For many children the community children's nursing team take on this role.”
Supporting Pupils in School with Medical Conditions

It is highly likely that some members of the school staff will be called upon to fill roles which were previously outside their experience, such as performing quite demanding medical procedures. If this is the case, training in these areas should be offered by medical staff. The emotional demands on members of the team around the child could become intense and mutual support will be beneficial. The more you can learn from each other, the better the team of professionals and family can meet the needs of the child. At all times, even when it feels difficult or beyond the normal practices of the school, the best interests of the child should be your guide.



People and organisations you might work with

Please click on a section to reveal more information, then click on the pop-up to close it

Education	Health	Social Care	Third Sector
Portage			
	Community children's nurse	Children with Disabilities teams	Condition specific charities
Local Authority (LA) SEND team			
	Specialist nursing teams	Short breaks service	Local Disability Forum
Education psychologists	Family GP	Looked After team	Contact a Family
Specialist teaching teams	Consultants		Religious and cultural groups
Home and Hospital Teaching Service	Paediatricians		Children's hospice services
Special School Outreach team	Occupational/physio/speech and language therapy services		Local parent carer forums
Education Transport Service			

Questions to consider

- Have you identified a lead worker from the school to liaise with family and other professionals?
- Do you know which other professionals are involved in the team around the child and how you can contact them?

- Have you started to consider possible models for flexible engagement with the child (contingency/parallel planning)?
- Have you considered ways to address the emotional demands on staff and peers, should the child's condition deteriorate?

- Are you responding quickly and flexibly to requests to contribute to assessments or changes to advice from other agencies?

Engaging and working collaboratively with other professionals and organisations: Stage three



In the end of life stage it is possible that the child may remain in school or be in contact with school right up to the point of death. Schools need to work closely with family and health professionals to ensure that all parties have a clear understanding of wishes, plans and roles in the event of death.

Of course, close liaison with the family remains paramount but requires an even greater degree of sensitivity and flexibility.

It is likely that some professionals who have been involved with the family may need to step back at this point and a new smaller core team identified to support the family. Schools will need to ensure that they are aware of revised health advice and are clear about the range of services involved in the end of life planning.

Counselling and bereavement services are likely to become significant partners during this stage, as may religious/spiritual organisations. Whilst it may initially appear that such services would be working with the family, it should not be forgotten that they may have an equally important role to play in school with friends, peers and staff both prior to and after death.

“Recognition of end of life is an important step within the care pathway and enables the families and professionals to focus and plan for the death of the child. Multi-agency care planning and joint working is fundamental to the care of the child at this stage.”

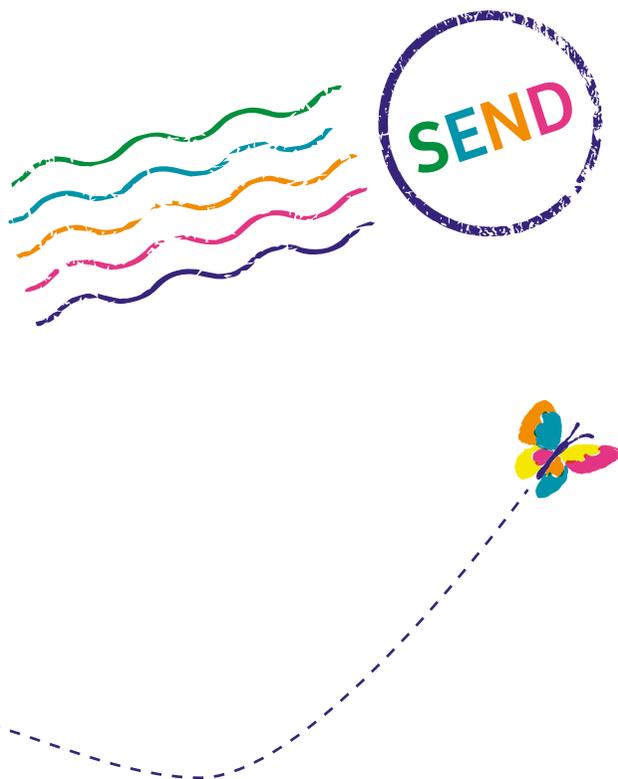
Together for Short Lives Core Care Pathway

Questions to consider

- Have you identified the school's role within the multi agency plan at this stage?
- Have you liaised with other professionals to ensure that you are clear about the family's wishes and revised health plans?
- Have you engaged with organisations and professionals who may be able to offer support/resources to the school community before and after the death of the child?
- Have you liaised with organisations that can provide religious/spiritual/cultural support as appropriate to the child, family and school?



Planning and implementing provision: Stage one



A child who has a life-limiting or life-threatening condition can arrive at the school post diagnosis, or be diagnosed during their time as a member of the school. In either event, it is vital that the school takes immediate steps to ensure the safety and wellbeing of the child. The first step will probably involve the parents and may be initiated by a phone call or request to meet.

The statutory guidance on supporting pupils at school with medical conditions quantifies the time which should be allowed in order to put in place the immediate plans for admission of a child to the school:

“For children starting at a new school, arrangements should be in place in time for the start of the relevant school term. In other cases, such as a new diagnosis or children moving to a new school mid-term, every effort should be made to ensure that arrangements are put in place within two weeks. Schools do not have to wait for a formal diagnosis before providing support to pupils. In cases where a pupil’s medical condition is unclear, or where there is a difference of opinion, judgements will be needed about what support to provide based on the available evidence. This would normally involve some form of medical evidence and consultation with parents. Where evidence conflicts, some degree of challenge may be necessary to ensure that the right support can be put in place”.

“Staff may be anxious that a pupil will die while at school. Although the family will understandably find it hard to talk about this, it will help to have a conversation with the family and the school in order to get a realistic perspective on how likely this is to happen... Involving the family when making any plans will make certain that their wishes are taken into account.”

Children at School with a Life Limiting or Life Threatening Illness

Individual health care planning should begin (See stage two for further detail). These plans should ensure that emergency procedures are agreed and understood. The guidance *Supporting Pupils at School with Medical Conditions*¹ offers a model process for developing Individual Healthcare Plans (IHCP). (See next page)

“It started with a terrified parent who came in to the nursery. We talked for two or three hours, then had to attend a series of meetings with health professionals, synthesise a prognosis for what school may look like for Henry and write a plan.”

SENCO

“Any member of school staff should know what to do and respond accordingly when they become aware that a pupil with a medical condition needs help.”

Supporting Pupils at School with Medical Conditions

1. Department for Education (2014). *Supporting Pupils at School with Medical Conditions*. Available to download from: <http://bit.ly/1ug0fn7>.

Questions to consider

- Have you responded quickly to the diagnosis, or the news that a child with a life-limiting or life-threatening condition will be admitted to school?
- Has a senior member of school staff been designated as the 'responsible person'?
- Have you arranged a meeting to discuss supporting the child in school? (An IHCP should be developed by parents, child, health care professionals, school staff and any others involved.)
- Has it been agreed who will lead on writing the IHCP?
- Are all members of staff clear about their response in a medical emergency?
- Have you identified staff training needs?

Process for developing Individual Healthcare Plans (IHCPs)

Parent or healthcare professional informs school that child has been newly diagnosed, or is due to attend new school, or is due to return to school after a long-term absence, or that needs have changed.



Headteacher or senior member of school staff to whom this has been delegated, co-ordinates meeting to discuss child's medical support needs; and identifies member of school staff who will provide support to pupil.



Meeting to discuss and agree on need for IHCP to include key school staff, child, parent, relevant healthcare professional and other medical/health clinician as appropriate (or to consider written evidence provided by them).



Develop IHCP in partnership – agree who leads on writing it. Input from healthcare professional must be provided.



School staff training needs identified.



Healthcare professional commissions/delivers training and staff signed-off as competent – review date agreed.



IHCP implemented and circulated to all relevant staff.



IHCP reviewed annually or when condition changes. Parent or healthcare professional to initiate.



Planning and implementing provision: Stage two



The *SEND Code of Practice*, 2014, established the 'Assess, Plan, Do, Review' cycle at the core of SEND planning in education provisions. This cycle offers a simple cycle for planning and implementation.

When a school finds itself working with a child with a life-threatening or life-limiting condition, the same cycle should be followed, though individual phases may take on a different character.

Planning is extremely important. While planning should be wide ranging (including a whole range of professional views), it should also be focused on a myriad of details. However, if wide ranging and detailed plans are allowed to mean rigid, things will fail. All planning needs to be characterised by flexibility, as the children we are thinking of will each follow their own path, which will include unexpected turns and unpredictable timescales.

Assess

Every family should receive a child and family centred multi-disciplinary and multi-agency assessment of their needs as soon as possible after diagnosis or recognition, and should have their needs reviewed at appropriate intervals. Education is unlikely to take the lead in this, but should certainly contribute to the process.

"Recent studies have shown that despite all the difficulties, with careful assessment and planning, family life can become enriched, purposeful and fulfilling as they reframe their lives to make the most of the time they have with their child."

Together for Short Lives Core Care Pathway

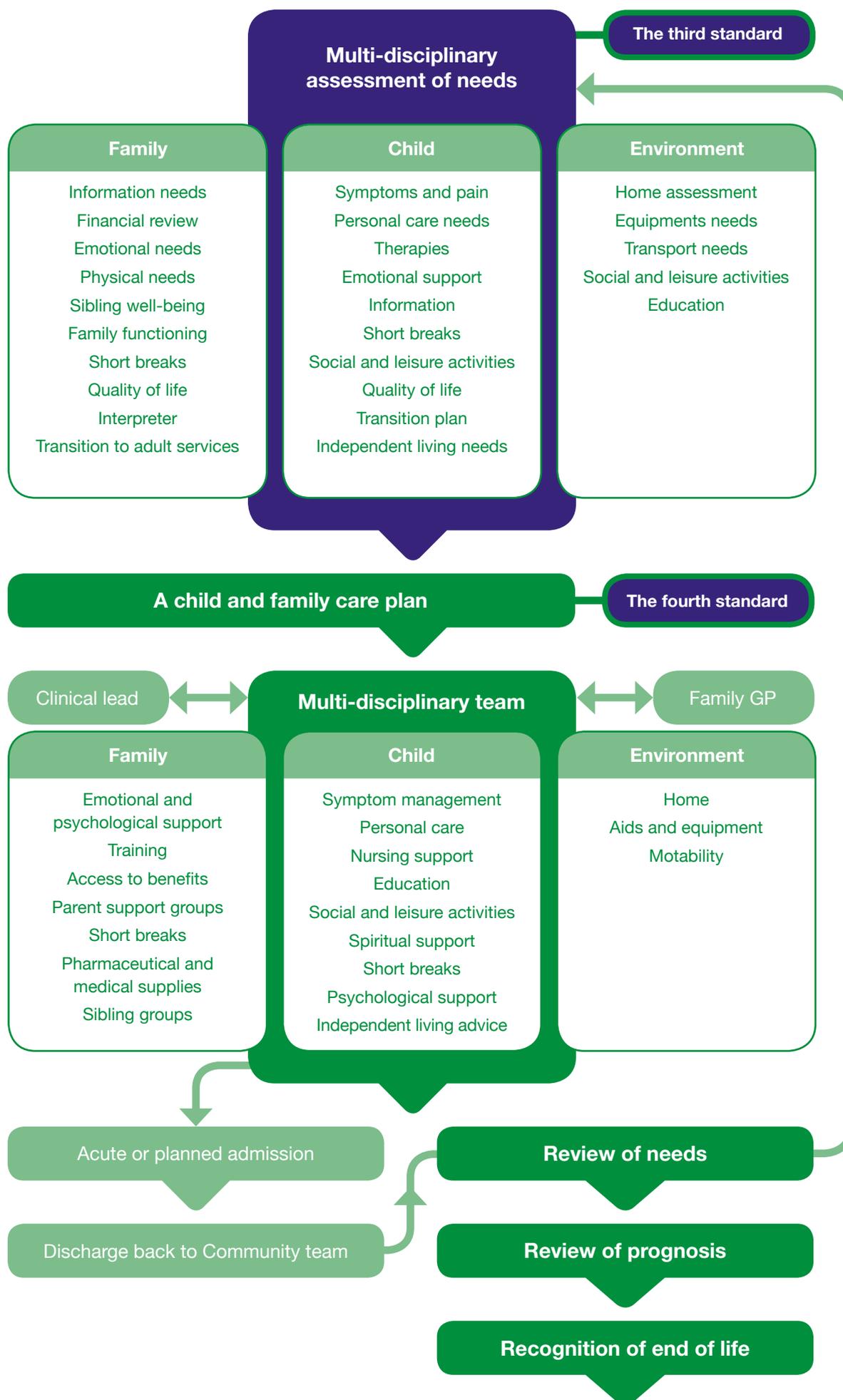
Assessment should be seen as an ongoing process rather than a single event. The aim of the assessment is to examine how all the individual factors have an impact on the child and family's quality of life and guide the delivery of specific services to meet the needs of the family.

For many families, the management of the child's symptoms will be their prime consideration. Most children will want to enjoy some kind of 'normality' with their peers, so school and leisure opportunities are an essential part of the assessment process.

The child's school may need support to enable the child to return or attend school for the first time, and the training and support needs of the staff should be considered to enable them to manage the child's care. It will be necessary to confirm how the child's personal and medical care needs will be met.



Core Care Pathway stage two:
Ongoing care



Plan

Planning for children who have a life-threatening or life-limiting condition is more complex and more likely to be revisited than in many other cases. It is good practice to engage in parallel planning, to try to prepare for the unexpected. A child may enjoy a lengthy period of stability, but this cannot be taken for granted. The child who was stable, with perfectly thought through provision, could experience a dramatic change to their needs overnight. Similarly, the school needs to be ready for the day when key staff are absent and systems are at risk of breakdown. If the school is part of a well thought through package of 24 hour care, it is not appropriate to send the child home because someone is off work. So, team work is again crucial, with second and third colleagues being able to step in as needed. Prior discussion of contingency plans with parents will help avoid crises and offer clarity about the situation in which parents would want you to contact them.

Planning for special circumstances is essential. Transition between phases of education, year groups, or between hospital and home need a review and sharing exercise. Similarly, access to out of school activities or residential experiences will require a careful risk assessment and detailed plan, including contingency plans.

When the SEND reforms were first proposed in 2011, there were high hopes that all disabled children of school age would be able to access a single Education, Health and Care (EHC) Plan. Under the final legislation, this is only available to children with SEN. As a result, professionals working with a child who has a life-limiting or life-threatening condition, but no SEN, could find themselves working with a number of complementary, but separate plans for education, health and care.

“Schools should ensure that their arrangements are clear and unambiguous about the need to support actively pupils with medical conditions to participate in school trips and visits, or in sporting activities, and not prevent them from doing so.”
Supporting Children at School with Medical Conditions

The most frequently employed plans are outlined below. What all plans should have in common is a commitment to placing the child’s best interests at their heart, a commitment to collaboration with the family and a flexible, co-ordinated approach which allows the needs and wishes of the child and parents to be respected. Whatever plans are put into place there should be co-ordinated, multi-agency assessment, regular review and flexible revision to meet changing circumstances and a clear focus on the needs and wishes of the child and family.

Multi-agency and multi disciplinary care plans

Every child and family should have a multi-disciplinary and multi-agency care plan, developed in partnership with them for the delivery of co-ordinated care to enhance family strengths and meet need. A multidisciplinary and multiagency team is identified in agreement with the family and delivered using key working principles. Wherever possible, this should involve all agencies involved in supporting the child and family, including the child’s community nursing team, allied health professionals, hospice, local acute and tertiary hospital services, education, social care and short break services.

Individual healthcare plans

Individual healthcare plans (IHCP) are school focused plans that help to ensure that schools effectively support pupils with medical conditions. They provide clarity about what needs to be done, when and by whom. They will be essential in cases where conditions fluctuate or where there is a high risk that emergency intervention will be needed, and where medical conditions are long-term and complex.

Advance Care Plan/Emergency healthcare plan

The Advance Care Plan (ACP) or emergency healthcare plan is a plan for life, giving information and guidance about the best way to care for the child, and to fulfil the child and family’s wishes in the event of intercurrent acute illness, and sudden deterioration in the child’s condition. It is more than just a wishes document; it has the status of a medical care plan. In addition it will provide a useful framework to support future discussions around care at the end of life.

Education Health and Care Plan

An Education Health and Care (EHC) Plan replaced the Statement of Special Educational Needs in September 2014. The idea behind the EHC is to enhance the co-ordination of the services which are involved in the life of a child and family. Not all children who have life-limiting or life-threatening conditions have special educational needs, though many do. However, the principles of the SEND Code of Practice will be familiar to schools and offer much practical guidance on working with families. The EHC should include a ‘tell it once’ profile of the child, as well as reference to the aspirations of the child and family. The plan should include an outcomes driven action plan, broken down into sections relating to Education, Health and Care needs. Should parents feel that any special educational provision included in an EHC is not being made, they can challenge the local authority through a first tier tribunal.

Do

Schools are likely to have a wide range of experience in supporting children with learning difficulties and similar strategies will apply in many ways when working with a child with complex medical needs. It is essential that teachers retain responsibility for the education of the child in their care. The school should not ‘delegate’ the child to support staff, however valuable the support may be in meeting particular needs. This becomes of even greater importance if the child has a life-limiting or life-threatening condition – it is essential that the school and other professionals develop a team approach to meeting these needs. Individuals can and will play lead roles, but they will need the support and back up of their colleagues.

The school is responsible for ensuring that the child’s needs are met and should liaise with other professionals to ensure that appropriate training and supervision are in place. Thinking ahead to a possible ‘worst case scenario’, the emotions and wellbeing of an individual who has been almost a lone worker with a child who dies are likely to suffer enormous harm. The support of a strong team is essential.

In a complex (and sometimes very large) organisation such as a children’s centre or a school, there is a delicate balance between sharing knowledge more widely than necessary and risking damage through a lack of knowledge by individual members of staff. At a simple level, the attendance team must be aware of possible irregular patterns of attendance and avoid any inappropriate and hurtful ‘standard action’. Similarly, normal expectations around homework and academic progress may need to be superseded by higher priorities.

“Think about the impact on the child if their main support worker is absent for a significant period, or leaves the school. But also, think of the impact on a member of staff who is asked to shoulder responsibility for a critically ill child on their own.”

SENCO

Risk assessment procedures should be carried out whenever necessary and the school should have regard to the guidelines around the management of medicines, enabling the child to manage their own needs where appropriate and keeping accurate records of medical procedures undertaken.

Further information will be found in *Supporting Pupils at School with Medical Conditions*, Section 35 and *Statutory Framework for the Early Years Foundation Stage*, Section 3.44-3.46¹.

Review

Assessment and planning are not one off events, they are part of an ongoing process of implementation, evaluation and revision. The needs of children with life-threatening and life-limiting conditions are likely to change more regularly than for most children, adding an extra dimension to the need to review the plan itself to check on the appropriateness of desired outcomes and associated provision. Reviews are likely to be multi-agency. Schools may be invited to contribute to such meetings, but may also feel the need to call meetings in their own context, to review the EHC or IHCP. When the school does host meetings, it is essential that they are helpful and productive. Always ensure that the staff who attend are able to contribute and have time to stay until all business has been completed. Try to do some pre-work if you know financial issues are going to arise.

“It is good when meetings are held in school, but they can tend to focus too much on education and feel like a school meeting with other people there. Sometimes school staff leave when the education part is finished.”

Children’s hospice team

Meetings which fall outside a planned cycle can arise for a number of reasons, which can render them crucial. A sudden deterioration in the child’s condition, or a return to school from a period of hospital care may generate a need for significant consideration of the provision previously made. It may be in such circumstances that a child who has been attending full time starts to attend only for part of the day or week. Or the priorities may change, making social engagement with peers a higher priority than academic progress.

Effective meetings have a clear purpose and a focused agenda. They are unlikely to fit into the normal calendar of reviews – urgent discussion of crucial developments cannot wait for an annual meeting.

“Imagine how upsetting it is for a parent when health and education professionals are arguing about who should pay for their child’s care.”

Children’s hospice team

1. *Statutory Framework for the Early Years Foundation Stage Section 3.44-3.46 DfE 31st March 2014: DFE-00337-2014.*

“The loss of what was their ‘normality’ and acceptance of the new and sometimes painful reality of changes in their child can be an emotional struggle. For many families, the need to review may relate to issues other than the health of the child. Services need to be able to provide sensitive, timely and appropriate support at times of change and instability to enable families to re-establish control.”

Together for Short Lives Core Care Pathway

To hold an effective meeting, a school should:

- have a clear purpose
- know who needs to contribute in person
- know who could contribute in writing
- ensure that the family knows the purpose and remit of the meeting
- co-ordinate the timing of the meeting with parents
- have an agreed timescale
- include the child’s voice whenever possible
- ensure that all parties understand the outcomes and actions

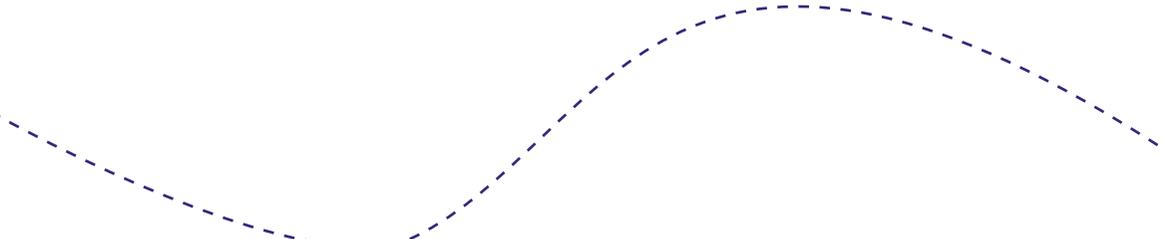
Those professionals working most closely with the family will need to be sensitive to their changing needs. Some families may need reviews only every six months, while others may need them much more often. It should also be possible for a family to request a review at any time.

“This little boy loves going to school, but he needs a lot of equipment and specialist care. After a crisis, health and education are still arguing about how to organise and pay for his care.”

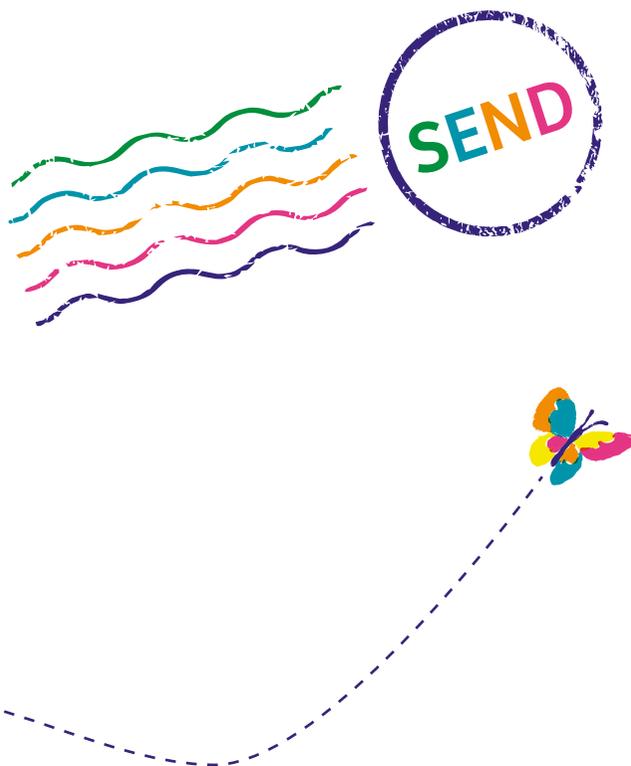
Children’s hospice team

Questions to consider

- Are you using the Assess, Plan, Do, Review cycle?
- Are you fully involving parents and the child in the planning and review process?
- Are school plans being informed by health advice?
- Are multi-agency meetings held in a timely and effective manner?
- Is planning shared with all key staff?
- Are training needs being met?



Planning and implementing provision: Stage three



Predicting the time when a child is likely to move into the end of life phase is not easy. There may have been a series of peaks and troughs in the child's condition, or the child may not return to their previous level of health following an illness. However, at some stage in their relationship with a child who has a life-limiting or life-threatening condition, a school may find itself involved in planning for the time when the child is no longer with them. The matters under discussion at this time include some of the most sensitive ever to be discussed, but failing to engage here will not help. While it is unlikely that school staff will be directly involved in discussions with the child and parents, they may find themselves continuing to play a role. The child may wish to continue with early years activities, or school work and this should be facilitated. He or she may want to continue seeing friends and carry on with other activities for as long as possible. There may be special wishes or goals to achieve, or the child may have an idea for the funeral, any of which could involve the school.

"Creating lasting memories is essential. Collecting school photographs, drawings, pictures, or stories made by the sick child, all help to create memories for the family when the child dies, and helps them in the grieving process. It will also be a lasting comfort for the parents to look at, and share with families and friends. It is also helpful for the children and teaching staff once the child dies."

Hospice Manager

"When approaching death, many children and young people are anxious to complete coursework or important projects. Teaching staff need to be aware and, where possible, make arrangements to facilitate this as well as being encouraged to mark work early and return promptly."

Children at School with a Life Limiting or Life Threatening Illness

Children at this stage of their journey may have an Advance Care Plan (ACP). The ACP is a record of the most sensitive thoughts and feelings that a child and family have about the care they wish to receive throughout their life and end of life. The school should be aware if a child has an ACP. If the child continues to engage with school, there is a possibility that they will experience a sudden deterioration in their condition, or will die on the premises. Where this is a possibility, the school should ensure that they have an emergency plan in place, so that all key staff know what actions to take and who to contact.

One crucial area for planning is how the school will react to support students when the child dies. It is very likely that the child will have siblings or a group of close friends in the school, while the tutor group, year group and broader school population will all feel the loss of a peer. Staff, especially those who have been most closely involved with the child, will also feel a huge sense of loss and grief. The school may have an ongoing relationship with the family, which will be redefined by the death.

In the event of death, the school will need to brief staff on how to inform the rest of the children. For younger children and especially those below the age of four, a more individual approach, including activities, will help them to make sense of the situation. Children over the age of four start to develop empathy and generally have cognitive and language skills to be able to express themselves and understand. Useful information can be found in *Supporting Children's Experiences of Loss and Separation*¹. For older children, the whole school should be informed at the same time (for example at the beginning of the day by form tutors) to ensure that children are not hearing rumours before they are told. Teachers should be told what form of words to use, what information to share and warned about possible reactions and questions from children. For groups of children with particular links with the child (for example their class or tutor group) it may be prudent to have two members of staff present to offer support to each other and the children who are likely to have the strongest reaction to the news. It will also be important to recognise that some members of staff's own emotional state might be upsetting or confusing to children if they were to break the news. School routines should be maintained as much as possible but opportunities should be made available for pupils and staff to have time to talk to specified members of staff for support.

It would be immensely valuable if the school and family were able to discuss issues such as what should be said to the pupils and how; how the school may be involved in the funeral and how the school may engage in commemorative activities. To have a plan in place to cover such sensitive matters and such emotionally charged times can do much to avoid difficulties or misunderstandings. Religious factors may be a very high priority to the family at this time.

"Even when too ill to attend school and unlikely to return, continued inclusion in school life may still be very welcome. Home visits from staff and/or pupils can give structure to the day and help give a sense of purpose. If visits are not possible, letters, cards, texts and emails may be welcomed. While staff may be apprehensive of intruding, families often feel that contact from school indicates that their child is still a valued member of the school community."

Children at School with a Life Limiting or Life Threatening Illness

Questions to consider

- If the child is attending school, is there an emergency plan in place?
- Have you planned how you will inform the school community in the event of the child's death?
- Have you (or a third party) discussed with parents their wishes about school involvement after death; in the funeral, commemorative events and fundraising activities for example.
- Do your plans include support or counselling for pupils and staff?



1. *Supporting Children's Experiences of Loss and Separation* Mary Barna Pre-School Learning Alliance ISBN/EAN: 9781907478130.

Support and training for the school community: Stage one



The realisation that a member of the school community has a life-limiting or life-threatening condition will probably come as a shock. It is likely to be the first time that many members of the community will have come so close to such a condition and they will have no precedents on which to draw from when they start to engage with this new circumstance. This is not true just of school children, many members of staff will be in the same situation.

Many members of staff will initially respond by worrying about ways in which they can do something 'wrong' or 'make things worse'. Their training will not have prepared them for this situation, so that is the obvious place to start. They will need clear information which includes facts about the child's condition, along with a fairly general prognosis about the future management of the condition. It is likely that the best people to talk to will be the child's parents, though school should be sensitive to the possible disruption of the family life if there has been a recent, shock diagnosis. Amongst the professionals involved, the community or specialist nursing team may be the best source of information and it may be possible for them to offer a short, focused session to raise understanding amongst the staff of the school.

"I felt *really* aware of my responsibility for him when we had a blip recently."

SENCO

"Anxieties often stem from fear of saying or doing the wrong thing and the emotional burden of caring for a student who is likely to die."

Children at School with a Life Limiting or Life Threatening Illness

Subject to what has been established already, discussions should take place with the family, to establish what they would like to be shared with the rest of the school. This will depend on a range of factors, including the age of the children, the nature of the condition and the prognosis for the child. The school will then need to give careful thought to what they wish to tell children; who they would want to deliver messages and in what contexts. It may be felt appropriate to involve specialist nurses or specialist charities in this work. Consideration should be given to normal, childish questions, such as "Will I catch it if I play with him?", "What happens if she dies?", or at an older level, "Is it OK to talk to him about things we want to do in the future?" All these questions and many more deserve and require an answer, so preparation by the school staff and discussion with the family will be helpful and important.

Staff who are asked to accept specific roles and responsibilities may need particular consideration as they adapt to their new context. Their emotional investment in the child may be the greatest amongst the staff of the school.

Once the school has established the context in which it is working, it should quickly be able to join fellow professionals in the type of planning exercises outlined above. This will start to identify the ways in which children and staff respond to and are affected by the new situation.



“The governing body should ensure that their arrangements give parents and pupils confidence in the school’s ability to provide effective support for medical conditions in school. The arrangements should show an understanding of how medical conditions impact on a child’s ability to learn, as well as increase their confidence and promote self-care. They should ensure that staff are properly trained to provide the support that pupils need.”

Supporting Pupils at School with Medical Conditions

It is highly likely that the school will need to access a significant amount of staff training in order to confidently and effectively meet the needs of the child. It must be remembered that it is the responsibility of the governing body to ensure that appropriate arrangements are put into place. This responsibility cannot be delegated to the SENCO – they may be entrusted with some of the vital actions, but the governors and headteacher/senior managers hold the responsibility.

In order to ensure that the child is able to enjoy their right to full access to school life, it may well be necessary for some members of staff to carry out health care procedures whilst the child is in school.

Guidance about non-health professionals being involved in medical procedures is provided by the Royal College of Nursing¹.

“Staff and carers should only agree to undertake these tasks if they feel competent and confident to do so.”

RCN

Any delegation of clinical tasks to non-health qualified staff must be undertaken within a robust governance framework which encompasses:

- initial training and preparation
- assessment and confirmation of competence
- confirmation of arrangements for ongoing support, updating of training and reassessment of competence

Non-health qualified staff are entitled to ask for additional education and training until they feel confident and competent. Health service managers must ensure there is access to support and advice.

The aim of a training programme should be to provide information and learning about both theoretical and practical aspects of the carer’s role. Opportunities must be provided for supervised practice before an assessment of competence by a suitably registered nurse. This process should take into account the views of the child or young person, parents and the views of the person being assessed.

Training should take place at two levels:

- general training around complex health needs
- training around a specific child and the procedures or the care that child will require

In the same way as information is shared on a need-to-know basis, training should be arranged on a general level for all staff working with a particular child and specific training for staff who will be supporting a child on a one-to-one basis.

“[The Nurse] remains accountable for the appropriateness of the delegation, for ensuring that the person who does the work is able to do it and that adequate supervision and support is provided.”

RCN

“Governing bodies should ensure that the school’s policy sets out clearly how staff will be supported in carrying out their role to support pupils with medical conditions, and how this will be reviewed. This should specify how training needs are assessed, and how and by whom training will be commissioned and provided.”

Supporting Pupils at School with Medical Conditions

Questions to consider

- Have you discussed with the family their views on sharing information about the child’s condition with staff and pupils?
- Have you put plans in place to share information, drawing on other organisations as appropriate?
- Have you identified training needs?
- Have you liaised with LA and health to access training?
- Is the governors’ policy fit for purpose?

1. Royal College of Nursing (2012). *Managing Children with Health Care Needs: Delegation of clinical procedures, training, accountability and governance issues.*

Support and training for the school community: Stage two



Staff

It is important that schools' support for their staff and children continues through stage two. In particular key members of staff are likely to feel 'a burden of responsibility' and without consideration may feel rather isolated and possibly suffer a level of anxiety and uncertainty. Such members of staff should be entitled to regular supervision to allow them to share their concerns and ensure that support plans remain effective. Through this system, the risk of creating isolated 'lone workers' should be averted. This is a very real concern, particularly as the main care support worker is very likely to be one of the lowest paid members of staff and should not feel solely accountable for the well-being of the child.

The emotional needs of the key members of staff and others with established links with the child and family will need to be considered.

Training for staff will continue to be a priority. The child's condition may change, requiring new or more frequent interventions. The school should ensure that a sufficient number of staff receive training to cover for absences and staff changes. It will be important for staff to maintain their skills and confidence. A rotating team of staff allocated by day or session can help to maintain skills and to avoid isolation and over reliance on one key member of staff. The children's community or specialist nursing teams are very likely to be the source of training and information for schools.

"The school's policy should be clear that any member of school staff providing support to a pupil with medical needs should have received suitable training. This should have been identified during the development or review of individual healthcare plans. Some staff may already have some knowledge of the specific support needed by a child with a medical condition and so extensive training may not be required. Staff who provide support to pupils with medical conditions should be included in meetings where this is discussed."

Supporting Pupils in School with Medical Conditions

Children

The child may respond to their condition and prognosis in a variety of ways. They may become very withdrawn, demanding, aggressive, depressed or fatalistic. Schools will need to demonstrate understanding and flexibility. The child's mental health may also be affected by their medical treatment. Side effects such as loss of hair may impact negatively upon their self esteem. All children are unique in their reaction and it will be important to liaise with the parents and other professionals in order to respond appropriately. It is possible that the child may be receiving psychological support outside of school but they may well identify a member of school staff as their confidant.

The first set of peers to consider may be the siblings who also attend the school (if any) and the close friends of the child. Schools will need to be aware of the emotional needs of these children and be mindful of the possible impact on their presentation in school. The use of Educational Psychology Service, Well Being Teams or Counselling Services may be of value in this area. School may be the only avenue for emotional support for these children.



“In addition to the educational impacts, there are social and emotional implications associated with medical conditions. Children may be self-conscious about their condition and some may be bullied or develop emotional disorders such as anxiety or depression around their medical condition. In particular, long-term absences due to health problems affect children’s educational attainment, impact on their ability to integrate with their peers and affect their general wellbeing and emotional health”

Supporting Pupils at School with Medical Conditions

The significant illness and possible death of a child within a school will impact upon the whole school community. Depending on their age, children are likely to ask difficult questions in school to which staff should be able to respond in accordance with the wishes of the child and the parent. It would be advisable for the school to have considered this and agreed some consistent responses.

There may be occasions when other children display insensitive or cruel behaviour toward the child with a life-limiting or life-threatening condition. Schools should consider how they may sensitively educate and inform the school community whilst respecting the level of confidentiality sought by the child and parents.

“Any siblings attending school will need consideration. They will be coping with their own emotions, a disrupted life and possibly fielding questions about their brother or sister”

Children at School with a Life Limiting or Life Threatening Illness

Questions to consider

- Do staff with specific support roles have access to supervision and support?
- Are training needs reviewed and being met?
- Are sufficient numbers of staff trained, so that a fail-safe system can be operated?
- Are the emotional needs of the child being met, as well as their medical needs?
- Are the needs of siblings and friends catered for in plans?
- Is the school vigilant to the threat of bullying and active in pre-empting it?



Support and training for the school community: Stage three



Sources of support and resources for children coping with bereavement

Sibs: www.sibs.org.uk

The Compassionate Friends: www.tcf.org.uk

Childhood Bereavement Network:
www.childhoodbereavementnetwork.org.uk

Child Bereavement UK: www.childbereavementuk.org

Winston's Wish: www.winstonswish.org.uk

Cruse Bereavement Care: www.cruse.org.uk

“The death of a parent or sibling is one of the most fundamental losses a child will ever facebereaved children need support to make sense of death and rebuild their lives.”

Winston's Wish

When it has become apparent that a child in the school is approaching death or the child has died, support for all members of the school community will be of paramount importance.

The well-being of siblings and close friends will need particular care and attention. There are organisations and support groups able to offer support at this time. Schools will need to be compassionate and understanding about the impact that the event will have upon the emotional state and behaviour of these children.

Schools may wish to build into their curriculum some discussion about life and death in order to respond to the inevitable questions that will be raised. This should be planned with advice from organisations with expertise in this area and be respectful of the family's wishes and religious/spiritual beliefs.

When informing the pupils about the death of a fellow pupil, allow them time to respond and ask questions. Involving children and staff in planning commemorative activities may also offer emotional support to the school and family.

Children will respond differently according to their age and understanding. A lot of useful information can be found in the publications of Child Bereavement UK, which can be accessed by following the link below:

www.childbereavementuk.org

“It is important for adults to understand the reactions they may observe and to be able to identify children or adolescents who require support. Parents, teachers, and other caregivers should also understand how their own grief reactions and responses to a loss may impact the experience of a child.”

National Association of Schools Psychologists

In particular, useful information about children's understanding about death at different ages will be found in **Children's Understanding of Death at Different Ages**. For older children, another useful resource can be found in **Death and grief: Supporting children and youth**.

The emotional health of staff who have worked closely with the child (particularly if they have felt a high level of responsibility for his care through Stage two) may be affected significantly. It may be, for some key support staff, that their career purpose has also been lost and there may be feelings of guilt/anger. Schools should be aware that some members of staff may need time to come to terms with the loss and that support may be required for some time after the death of the child. Enabling the school and staff to maintain links with the family (if appropriate) may be helpful.

“Schools can help set a positive attitude with the focus on living rather than dying by acknowledging the vital role of a school in the life of a child, however ill they are, and the role of the child in the life of the school.”

Children at School with a Life Limiting or Life Threatening Illness

Multi-agency and multi-disciplinary care plans



Multi-agency and multi-disciplinary care plans should be comprehensive and include the following elements:

- Details of the professionals involved plus contact details and identified lead professional duties.
- Identified multi-agency and multi-disciplinary team.
- Step by step goal-focused protocol for each aspect of clinical care.
- Personal care including a privacy and dignity plan.
- Dietary plan.
- Allied health professional plans.
- Emotional, spiritual and psychological care plan for the child and family.
- An outline of what will be provided by each service.
- Details of how to access services in and out of hours.
- Advance care plan including symptom management plan.
- Emergency care plan or escalation plan.
- Risk assessments, including moving and handling.
- Environmental assessments.
- Agreement of care including parent and staff responsibilities.
- Information pertinent to the child's needs.
- Equipment information including manuals and guidelines.
- Stock lists.
- Competency based education plan for parents and staff.
- Play and education plans.
- Short breaks plan.
- Communication diary.
- Clinical updates.
- Policies where appropriate, for example on washing hands.
- Checklists for daily routine.
- Family strengths.



Individual healthcare plans



Individual healthcare plans (and their review) may be initiated, in consultation with the parent, by a member of school staff or a healthcare professional involved in providing care to the child. Plans should be drawn up in partnership between the school, parents and a relevant healthcare professional, for example the school, specialist or children's community nurse, who can best advise on the particular needs of the child. Children should also be involved whenever appropriate. The aim should be to capture the steps which a school should take to help the child manage their condition and overcome any potential barriers to getting the most from their education. Partners should agree who will take the lead in writing the plan, but responsibility for ensuring it is finalised and implemented rests with the school. **The governing body should ensure that plans are reviewed at least annually, or earlier if evidence is presented that the child's needs have changed. They should be developed with the child's best interests in mind and ensure that the school assesses and manages risks to the child's education, health and social wellbeing, and minimises disruption.** Where the child has a special educational need identified in a statement or education health and care (EHC) plan, the individual healthcare plan should be linked to or become part of that statement or EHC plan.

Where a child is returning to school following a period of hospital education or alternative provision (including home tuition), schools should work with the local authority and education provider to ensure that the individual healthcare plan identifies the support the child will need to reintegrate effectively.

When deciding what information should be recorded on individual healthcare plans, the governing body should consider the following elements.

- The medical condition, its triggers, signs, symptoms and treatments.
- The child's resulting needs, including medication (dose, side effects and storage) and other treatments, time, facilities, equipment, testing, access to food and drink where this is used to manage their condition, dietary requirements and environmental issues, for example crowded corridors and travel time between lessons.
- Specific support for the child's educational, social and emotional needs. For example, how absences will be managed, requirements for extra time to complete exams, use of rest periods or additional support in catching up with lessons and counselling sessions.
- The level of support needed (some children will be able to take responsibility for their own health needs) including in emergencies. If an older child is self-managing their medication, this should be clearly stated with appropriate arrangements for monitoring.
- Who will provide this support, their training needs, expectations of their role and confirmation of proficiency to provide support for the child's medical condition from a healthcare professional; and cover arrangements for when they are unavailable.
- Who in the school needs to be aware of the child's condition and the support required.

- Arrangements for written permission from parents and the senior manager or headteacher for medication to be administered by a member of staff, or self-administered by an older child during school hours.
- Separate arrangements or procedures required for school trips or other school activities outside of the normal school timetable that will ensure the child can participate, for example risk assessments.
- Where confidentiality issues are raised by the parent/child, the designated individuals to be entrusted with information about the child's condition.
- What to do in an emergency, including whom to contact, and contingency arrangements. Some children may have an emergency healthcare plan prepared by their lead clinician that could be used to inform development of their individual healthcare plan.

Useful resources

Advance care plans

Advance care plans



Good communication and co-ordination between all relevant professionals and local services is essential to ensure that staff and families are aware of what care is available and that they are able to make informed choices. All staff should be aware if a child has an Advance Care Plan to inform them of their wishes around care and place of care and death.

An Advance Care Plan (ACP) is a record of the most sensitive thoughts and feelings that a child and family have about the care they wish to receive throughout their life and end of life. ACPs allow children, young people and their families to communicate their wishes for life and wishes for end of life, alongside management of acute and intercurrent illnesses. The difficult conversations are best carried out by professionals with advanced communication skills, ideally who are known to and trusted by the family.

An ACP can help families and professionals think about choices at the end of life. It can set out what actions should be taken when a child develops potentially life-threatening complications. Actions will be discussed and agreed by the child (when appropriate) and the family. It is important that children and their families have choices in the care they receive, and their place of care as they approach the end of their life. An ACP can help minimise inappropriate admissions and interventions, as well as facilitate choice. It is important to discuss the different models and approaches to care across different settings: hospice, home and hospital. It is essential that all available options are explored fully so that families are able to make realistic choices.

Advance care planning should involve decisions about resuscitation status and precise details about what the family want and do not want should be explored. It may be possible to develop a written Personal Resuscitation Plan with the lead consultant and other people looking after the child, to assist in communication between different professionals in different settings. This plan should also be shared with the local ambulance service.



Glossary



Children's palliative care

Palliative care for children with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement. (Together for Short Lives *Core Care Pathway*, 2013).

Care of the dying

Care of the dying is the care of the patient and family in the last days and hours of life. It incorporates four main types of care: physical, psychological, social and spiritual, and supports the family at that time and into bereavement.

Care Plan

A record of the health and/or social care services that are being provided to a child or young person to help them manage a disability or health condition. The plan will be agreed with the child's parents or the young person and may be contained within a patient's medical record or maintained as a separate document. Care Plans are also maintained by local authorities for looked after children – in this instance the Care Plan will contain a Personal Education Plan in addition to the health and social care elements.

Children

Throughout this document, the term 'children' is used to describe babies, children and young people up to the age of 25.

Children's hospice services

Children's hospice services provide palliative care for children and young people with life-limiting conditions and their families. Delivered by a multi-disciplinary team and in partnership with other agencies, children's hospice services aim to meet the needs of both the child and family – physical, emotional, social and spiritual – through a range of services:

- 24 hour end of life care.
- Support for the entire family (including siblings, grandparents and the extended family).
- Bereavement support.
- 24 hour access to emergency care.
- Specialist short break care.
- 24 hour telephone support.
- Practical help, advice and information.
- Provision of specialist therapies, including physiotherapy as well as play and music therapy.
- Provision of information, support, education and training where needed to carers.

Children's hospice services deliver this care in the home (commonly termed 'hospice at home service') and/or in a purpose built building.

Complex care/continuing care

Complex care, sometimes known as continuing care, is an individualised package of care beyond what is available through standard health services. It is provided to children with highly complex healthcare needs or intense nursing care needs.

Community services

Community services refer to a service that an individual or organisation performs within the local community. This might include community children's nurses (CCNs) who deliver nursing care and support within the local community including visiting a patient's home. Community services may also include some of the services delivered by the local council.

Disability

The Equality Act 2010 defines disability as when a person has a "physical or mental impairment which has a substantial and long term adverse effect on that person's ability to carry out normal day to day activities." Some specified medical conditions, HIV, multiple sclerosis and cancer are all considered as disabilities, regardless of their effect.

Early years provider

A provider of early education places for children under five years of age. This can include state-funded and private nurseries as well as child minders.



Education, Health and Care plan (EHC plan)

An EHC plan details the education, health and social care support that is to be provided to a child or young person who has SEN or a disability. It is drawn up by the local authority after an EHC needs assessment of the child or young person has determined that an EHC plan is necessary, and after consultation with relevant partner agencies.

End of life

The end of life phase begins when a judgement is made that death is imminent. It may be the judgement of the health or social care team, but it is often the child/young person or their family who first recognises its beginning.

End of life care

End of life care is care that helps all those with an advanced, progressive, incurable illness to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition, this includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both child/young person and their family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family into bereavement. This is not confined to specialist services but includes those services provided by any health or social care professional in any setting.

Family

The term 'family' includes parents, other family members involved in the child's care, or other carers who are acting in the role of parents. Family includes informal carers and all those who matter to the child/young person.

Hospice at home

Hospice at home is a term commonly used to describe a service which brings skilled, practical children's palliative care into the home environment. Hospice at home works in partnership with parents, families and other carers.

Key working

Key working or care co-ordination is a service, involving two or more agencies, that provides disabled children and young people and their families with a system whereby services from different agencies are co-ordinated. It encompasses individual tailoring of services based on assessment of need, inter-agency collaboration at strategic and practice levels and a named key worker for the child and their family.

Life-limiting/life-shortening conditions

Life-limiting conditions, sometimes known as life-shortening conditions, are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers.

Life-threatening conditions

Life-threatening conditions are those for which curative treatment may be possible but can fail, such as children with cancer. Children in long-term remission or following successful curative treatment are not included.

Needs-led

Needs-led is the term used to describe services provided on the basis of the needs of the patient and family, rather than as a result of assessing the resources that are available.

Parents

The term 'parents' is used to mean any carer for a child whether that is a married or unmarried couple, a single parent, guardian or foster parent.

School

The term 'school' is used to mean any educational setting, including nursery, pre-school, Early Years provider, primary, secondary or tertiary establishment.

Special Educational Needs

A child or young person has SEN if they have a learning difficulty or disability which calls for special educational provision to be made for him or her. A child of compulsory school age or a young person has a learning difficulty or disability if he or she has a significantly greater difficulty in learning than the majority of others of the same age, or has a disability which prevents or hinders him or her from making use of educational facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions.

Death and grief: Supporting children and youth



This document is adapted from *Death and Grief in the Family: Tips for Parents*¹; *Helping Children at Home and School III: Handouts for Families and Educators*²; and from materials posted on the National Association of School Psychologists (NASP) website after September 11, 2001.

Death and loss within a school community can affect anyone, particularly children and adolescents. Whether the death of a classmate, family member, or staff member, students may need support in coping with their grief. Reactions will vary depending on the circumstances of the death and how well known the deceased is both to individual students and to the school community at-large. Students who have lost a family member or someone close to them will need particular attention. It is important for adults to understand the reactions they may observe and to be able to identify children or adolescents who require support. Parents, teachers, and other caregivers should also understand how their own grief reactions and responses to a loss may impact the experience of a child.

Grief reactions

There is no right or wrong way to react to a loss. No two individuals will react in exactly the same way. Grief reactions among children and adolescents are influenced by their developmental level, personal characteristics, mental health, family and cultural influences, and previous exposure to crisis, death, and loss. However, some general trends exist that can help adults understand typical and atypical reactions of bereaved children. Sadness, confusion, and anxiety are among the most common grief responses and are likely to occur for children of all ages.

The grief process

Although grief does not follow a specified pattern, there are common stages that children and adolescents may experience with varying sequencing and intensity. The general stages of the grief process are:

- denial (unwillingness to discuss the loss)
- anger or guilt (blaming others for the loss)
- sorrow or depression (loss of energy, appetite, or interest in activities)
- bargaining (attempts to regain control by making promises or changes in one's life)
- acceptance or admission (acceptance that loss is final, real, significant, and painful)

Grief reactions of concern

The above behaviours are expected and natural reactions to a loss. However, the following behaviours may warrant further attention:

Preschool level:

- Decreased verbalization.
- Increased anxiety (eg clinginess, fear of separation).
- Regressive behaviours (eg bedwetting, thumb-sucking).

Elementary school level:

- Difficulty concentrating or inattention.
- Somatic complaints (eg headaches, stomach problems).
- Sleep disturbances (eg nightmares, fear of the dark).
- Repeated telling and acting out of the event.
- Withdrawal.
- Increased irritability, disruptive behaviour, or aggressive behaviour.
- Increased anxiety (eg clinging, whining).
- Depression, guilt or anger.

1. National Association of School Psychologists. *Death and Grief in the Family: Tips for Parents*. Available to download from: www.nasponline.org/resources/principals/nasp_griefparents.pdf.

2. National Association of School Psychologists. *Death and Grief in the Family. Helping Children at Home and School III: Handouts for Families and Educators*. Available to download from: www.nasponline.org/publications/booksproducts/hchs3.aspx.



Middle and high school level:

- Flashbacks.
- Emotional numbing or depression.
- Nightmares.
- Avoidance or withdrawal.
- Peer relationship problems.
- Substance abuse or other high-risk behaviour.

Signs that additional help is needed

Adults should be particularly alert to any of the following as indicators that a trained mental health professional (school psychologist or counsellor) should be consulted for intervention and possible referral:

- Severe loss of interest in daily activities (eg extracurricular activities and friends).
- Disruption in ability to eat or sleep.
- School refusal.
- Fear of being alone.
- Repeated wish to join the deceased.
- Severe drop in school achievement.
- Suicidal references or behaviour.

Risk factors for increased reactions

Some students (and adults) may be a greater risk for grief reactions that require professional intervention. This includes individuals who:

- were very close to the person(s) who died
- were present when the person died
- have suffered a recent loss
- have experienced a traumatic event
- are isolated or lack a personal support network
- suffer from depression, Post Traumatic Stress Disorder, or other mental illness

Keep in mind that groups, particularly adolescents, can experience collective or even vicarious grief. Students may feel grief, anxiety or stress because they see classmates who were directly affected by a loss, even if they didn't personally know the deceased. Additional risk factors include the deceased being popular or well-known, extensive media coverage, a sudden or traumatic death, murders or suicides.

Supporting grieving children and youth

How adults in a family or school community grieve, following a loss, will influence how children and youth grieve. When adults are able to talk about the loss, express their feelings, and provide support for children and youth in the aftermath of a loss, they are better able to develop healthy coping strategies.

The following points should be encouraged to adults:

- Talk about the loss. This gives children permission to talk about it, too.
- Ask questions, to determine how children understand the loss, and gauge their physical and emotional reactions.
- Listen patiently. Remember that each person is unique and will grieve in his or her own way.
- Be prepared to discuss the loss repeatedly. Children should be encouraged to talk about, act out, or express through writing or art the details of the loss, as well as their feelings about it, about the deceased person and about other changes that have occurred in their lives as a result of the loss.
- Give children important facts about the event at an appropriate developmental level. This may include helping children accurately understand what death is. For younger children, this explanation might include helping them to understand that the person's body has stopped working and will never again work.
- Help children understand the death and intervene to correct false perceptions about the cause of the event, ensuring that they do not blame themselves or others for the situation.
- Provide a model of healthy mourning by being open about your own feelings of sadness and grief.
- Create structure and routine for children, so they experience predictability and stability.



- Take care of yourself, so you can assist the children and adolescents in your care. Prolonged, intense grieving, or unhealthy grief reactions (such as substance abuse) will inhibit your ability to provide adequate support.
- Acknowledge that it will take time to mourn and that bereavement is a process that occurs over months and years. Be aware that normal grief reactions often last longer than six months, depending on the type of loss and proximity to the child.
- Take advantage of school and community resources such as counselling, especially if children and young people do not seem to be coping well with grief and loss.



Tips for children and teens with grieving friends and classmates

Seeing a friend try to cope with a loss may scare or upset children who have had little or no experience with death and grieving. Some suggestions teachers and parents can provide to children and youth to deal with this 'secondary' loss:

- Particularly with younger children, it will be important to help clarify their understanding of death.
- See tips above under 'helping children cope'.
- Seeing their classmates' reactions to loss may bring about some fears of losing their own parents or siblings. Children need reassurance from caretakers and teachers that their own families are safe. For children who have experienced their own loss (previous death of a parent, grandparent, sibling), observing the grief of a friend can bring back painful memories. These children are at greater risk of developing more serious stress reactions and should be given extra support as needed.
- Children (and many adults) need help in communicating condolence or comfort messages.
- Provide children with age-appropriate guidance for supporting their peers. Help them decide what to say (eg "Steve, I am so sorry about your father. I know you will miss him very much. Let me know if I can help you with your paper route....") and what to expect (see "expressions of grief" above).

- Help children anticipate some changes in friends' behaviour. It is important that children understand that their grieving friends may act differently, may withdraw from their friends for a while, might seem angry or very sad, but that this does not mean a lasting change in their relationship.
- Explain to children that their 'regular' friendship may be an important source of support for friends and classmates. Even normal social activities such as inviting a friend over to play, going to the park, playing sports, watching a movie, or a trip to the mall may offer a much needed distraction and sense of connection and normality.
- Children need to have some options for providing support—it will help them deal with their fears and concerns if they have some concrete actions that they can take to help. Suggest making cards, drawings or helping with chores or homework. Older teens might offer to help the family with some shopping, cleaning, errands or with babysitting for younger children.
- Encourage children who are worried about a friend to talk to a caring adult. This can help alleviate their own concern or potential sense of responsibility for making their friend feel better. Children may also share important information about a friend who is at risk of more serious grief reactions.
- Parents and teachers need to be alert to children in their care who may be reacting to a friend's loss of a loved one. These children will need some extra support to help them deal with the sense of frustration and helplessness that many people are feeling at this time.

The Equality Act 2010



Extracts from “The Equality Act 2010 and schools; Departmental advice for school leaders, school staff, governing bodies and local authorities”, (DfE, May 2014)

Chapter 4 – Disability

4.1 As mentioned in Chapter 1, and as in previous equality legislation, the disability provisions in this act are different from those for other protected characteristics in a number of ways.

4.2 The overriding principle of equality legislation is generally one of equal treatment – i.e. that you must treat a black person no less well than a white person, or a man as favourably as a woman. However, the provisions relating to disability discrimination are different in that you may, and often must, treat a disabled person more favourably than a person who is not disabled and may have to make changes to your practices to ensure, as far as is reasonably possible, that a disabled person can benefit from what you offer to the same extent that a person without that disability can. So in a school setting the general principle is that you have to treat male and female, black and white, gay and straight pupils equally – but you may be required to treat disabled pupils differently. Discrimination is also defined rather differently in relation to disability.

Provisions relating to disability

4.3 The disability provisions in the Equality Act mainly replicate those in the former Disability Discrimination Act (DDA). There are some minor differences as follows:

- Unlike the DDA the Equality Act does not list the types of day to day activities which a disabled person must demonstrate that they cannot carry out, thus making the definition of disability less restrictive for disabled people to meet.
- Failure to make a reasonable adjustment can no longer be defended as justified. The fact that it must be reasonable provides the necessary test.
- Direct discrimination against a disabled person can no longer be defended as justified – bringing it into line with the definition of direct discrimination generally.
- From September 2012 schools and local authorities have a duty to supply auxiliary aids and services as reasonable adjustments where these are not being supplied through Special Educational Needs (SEN) statements or from other sources (see paragraphs 4.15 - 4.20). In practice this will already be being done in many cases.

Definition of disability

4.4 The act defines disability as when a person has a ‘physical or mental impairment which has a substantial and long term adverse effect on that person’s ability to carry out normal day to day activities.’ Some specified medical conditions, HIV, multiple sclerosis and cancer are all considered as disabilities, regardless of their effect.

4.5 The act sets out details of matters that may be relevant when determining whether a person meets the definition of disability. Long term is defined as lasting, or likely to last, for at least 12 months.

Unlawful behaviour with regard to disabled pupils

4.6 Chapter 1 (1.17 – 1.24) explains the general definitions in the act of direct discrimination, indirect discrimination, victimisation and harassment. The rather different and more complex provisions that apply in the case of disability are set out here.

Direct discrimination

4.7 A school must not treat a disabled pupil less favourably simply because that pupil is disabled – for example by having an admission bar on disabled applicants.

4.8 A change for schools in this act is that there can no longer be justification for direct discrimination in any circumstances. Under the DDA schools could justify some direct discrimination – if it was a proportionate means of meeting a legitimate aim. What the change means is that if a school discriminates against a person purely because of his or her disability (even if they are trying to achieve a legitimate aim) then it would be unlawful discrimination as there can be no justification for their actions.

Indirect discrimination

4.9 A school must not do something which applies to all pupils but which is more likely to have an adverse effect on disabled pupils only – for example having a rule that all pupils must demonstrate physical fitness levels before being admitted to the school – unless they can show that it is done for a legitimate reason, and is a proportionate way of achieving that legitimate aim.



Discrimination arising from disability

4.10 A school must not discriminate against a disabled pupil because of something that is a consequence of their disability – for example by not allowing a disabled pupil on crutches outside at break time because it would take too long for her to get out and back. Like indirect discrimination, discrimination arising from disability can potentially be justified.

Harassment

4.11 A school must not harass a pupil because of his disability – for example, a teacher shouting at the pupil because the disability means that he is constantly struggling with class-work or unable to concentrate.

Disability Equality Duty

4.12 Schools previously had a statutory duty which required them to take proactive steps to tackle disability discrimination, and promote equality of opportunity for disabled pupils. Under the Equality Act, this has been replaced by the general equality duty and the specific duties – covered in chapter 5 of this guidance.

Reasonable adjustments and when they have to be made

4.13 The duty to make reasonable adjustments applies only to disabled people. For schools the duty is summarised as follows:

- Where something a school does places a disabled pupil at a disadvantage compared to other pupils then the school must take reasonable steps to try and avoid that disadvantage.

- Schools will be expected to provide an auxiliary aid or service for a disabled pupil when it would be reasonable to do so and if such an aid would alleviate any substantial disadvantage that the pupil faces in comparison to non-disabled pupils.

Schools are not subject to the requirement of reasonable adjustment duty concerned with making alterations to physical features because this is already considered as part of their planning duties.

Auxiliary aids and services

4.14 The duty to provide auxiliary aids as part of the reasonable adjustment duty is a change for all schools from September 2012 and also extends to maintaining local authorities.

4.15 Many disabled children will have a SEN and may need auxiliary aids which are necessary as part of their SEN provision; in some circumstances as part of a formal SEN statement. These aids may be provided in the school under the SEN route, in which case there will be no need for the school to provide those aids as part of their reasonable adjustment duty.

4.16 Schools will have to consider whether to provide auxiliary aids as a reasonable adjustment for disabled children. This will particularly be the case where a disabled child does not have an SEN statement or where the statement does not provide the auxiliary aid or service.

4.17 There should be no assumption, however, that if an auxiliary aid is not provided under the SEN regime then it must be provided as a reasonable adjustment. Similarly, whilst schools and LAs are under the same reasonable adjustment duty, there should be no assumption that where it is unreasonable for a school to provide an auxiliary aid or service, for example on cost grounds, it would then be reasonable for the local authority to provide it. All decisions would depend on the facts of each individual case. The nature of the aid or service, and perhaps also the existence of local arrangements between schools and local authorities, will help to determine what would be reasonable for the school or the LA to provide. For example, where there is a centrally organised visual or hearing impairment service it may be reasonable for the local authority to provide more expensive aids or support through that service but not reasonable for an individual school to have to provide them.

4.18 The term ‘auxiliary aids’ found in the Equality Act 2010 covers both auxiliary aids and services but there is no legal definition for what constitutes auxiliary aids and services. Considering the everyday meaning of the words, is, however, helpful. Legal cases have referred to the Oxford English Dictionary definition of auxiliary as “helpful, assistant, affording aid, rendering assistance, giving support or succour” and that auxiliary aids and services “are things or persons which help”. Examples of what may be considered an auxiliary aid could be; hearing loops; adaptive keyboards and special software. However the key test is reasonableness and what may be reasonable for one school to provide may not be reasonable for another given the circumstances of each case.



4.19 Some disabled children will have a need for auxiliary aids which are not directly related to their educational needs or their participation in school life, for example, things which are generally necessary for all aspects of their life, such as hearing aids. It is likely to be held that it would be unreasonable for a school to be expected to provide these auxiliary aids.

Making reasonable adjustments

4.20 The Equality and Human Rights Commission (EHRC) has published guidance on the auxiliary aids duty which includes advice on when it would be reasonable for schools to have to make adjustments and what factors a school should take into account in its assessment of whether or not it would be reasonable to make any particular adjustment. The guidance is available at

www.equalityhumanrights.com/legal-and-policy/equality-act/equality-act-codes-of-practice/.

4.21 A minor change for schools is that a failure to make a reasonable adjustment cannot now be justified, whereas under the previous disability discrimination legislation it could be. However this change should not have any practical effect due to the application of the reasonableness test – i.e. if an adjustment is reasonable then it should be made and there can be no justification for why it is not made. Schools will not be expected to make adjustments that are not reasonable.

4.22 In addition to having a duty to consider reasonable adjustments for particular individual disabled pupils, schools will also have to consider potential adjustments which may be needed for disabled pupils generally as it is likely that any school will have a disabled pupil at some point. However, schools are not obliged to anticipate and make adjustments for every imaginable disability and need only consider general reasonable adjustments – eg being prepared to produce large font papers for pupils with a visual impairment even though there are no such pupils currently admitted to the school. Such a strategic and wider view of the school's approach to planning for disabled pupils will also link closely with its planning duties (covered in 4.21).

4.23 The act does not set out what would be a reasonable adjustment or a list of factors to consider in determining what is reasonable. It will be for schools to consider the reasonableness of adjustments based on the circumstances of each case. However, factors a school may consider when assessing the reasonableness of an adjustment may include the financial or other resources required for the adjustment, its effectiveness, its effect on other pupils, health and safety requirements, and whether aids have been made available through the Special Educational Needs route.

4.24 Cost will inevitably play a major part in determining what is reasonable and it is more likely to be reasonable for a school with substantial financial resources to have to make an adjustment with a significant cost, than for a school with fewer resources. For example, a small rural primary school may not be able to provide specialised IT equipment for any disabled pupils who may need it and it may not be reasonable for the school to provide that equipment. On the other hand, a much larger school might reasonably be expected to provide it.

4.25 Often, though, effective and practicable adjustments for disabled pupils will involve little or no cost or disruption and are therefore very likely to be reasonable for a school to have to make.

4.26 Schools generally will try to ensure that disabled pupils can play as full a part as possible in school life and the reasonable adjustments duty will help support that. However, there will be times when adjustments cannot be made because to do so would have a detrimental effect on other pupils and would therefore not be reasonable – for example, if a school put on a geology field trip which necessarily involved climbing and walking over rough ground and after fully considering alternatives to accommodate a disabled pupil in a wheelchair who could not take part it determined that there was no viable alternative or way of enabling the disabled pupil to participate or be involved, it would not have to cancel the trip as originally planned. This is unlikely to constitute direct discrimination or failure to make a reasonable adjustment.

4.27 The reasonable adjustments duties on schools are intended to complement the accessibility planning duties (covered in 4.28 - 31) and the existing SEN statement provisions which are part of education legislation, under which local authorities have to provide auxiliary aids to pupils with a statement of special educational need.



Schools' duties around accessibility for disabled pupils

4.28 Schools and LAs need to carry out accessibility planning for disabled pupils. These are the same duties as previously existed under the DDA and have been replicated in the Equality Act 2010.

4.29 Schools must implement accessibility plans which are aimed at:

- increasing the extent to which disabled pupils can participate in the curriculum
- improving the physical environment of schools to enable disabled pupils to take better advantage of education, benefits, facilities and services provided
- improving the availability of accessible information to disabled pupils

4.30 Schools will also need to have regard to the need to provide adequate resources for implementing plans and must regularly review them. An accessibility plan may be a freestanding document but may also be published as part of another document such as the school development plan.

4.31 OFSTED inspections may include a school's accessibility plan as part of their review.

Appendix 5 (B): Extracts from Equality Act 2010: Guidance on matters to be taken into account in determining questions relating to the definition of disability

The act defines a disabled person as a person with a disability. A person has a disability for the purposes of the act if he or she has a physical or mental impairment and the impairment has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities (S6(1)).

A2. This means that, in general:

- the person must have an impairment that is either physical or mental (see paragraphs A3 to A8)
- the impairment must have adverse effects which are substantial (see Section B)
- the substantial adverse effects must be long-term (see Section C)
- the long-term substantial adverse effects must be effects on normal day-to-day activities (see Section D)

This definition is subject to the provisions in Schedule 1 (Sch1).

All of the factors above must be considered when determining whether a person is disabled.

Meaning of 'impairment'

A3. The definition requires that the effects which a person may experience must arise from a physical or mental impairment. The term mental or physical impairment should be given its ordinary meaning. It is not necessary for the cause of the impairment to be established, nor does the impairment have to be the result of an illness. In many cases, there will be no dispute whether a person has an impairment. Any disagreement is more likely to be about whether the effects of the impairment are sufficient to fall within the definition and in particular whether they are long-term. Even so, it may sometimes be necessary to decide whether a person has an impairment so as to be able to deal with the issues about its effects.

A4. Whether a person is disabled for the purposes of the act is generally determined by reference to the effect that an impairment has on that person's ability to carry out normal day-to-day activities. An exception to this is a person with severe disfigurement (see paragraph B24). It is not possible to provide an exhaustive list of conditions that qualify as impairments for the purposes of the act. Any attempt to do so would inevitably become out of date as medical knowledge advanced.



A5. A disability can arise from a wide range of impairments which can be:

- sensory impairments, such as those affecting sight or hearing
- impairments with fluctuating or recurring effects such as rheumatoid arthritis, myalgic encephalitis (ME), chronic fatigue syndrome (CFS), fibromyalgia, depression and epilepsy
- progressive, such as motor neurone disease, muscular dystrophy, and forms of dementia
- auto-immune conditions such as systemic lupus erythematosus (SLE)
- organ specific, including respiratory conditions, such as asthma, and cardiovascular diseases, including thrombosis, stroke and heart disease; developmental, such as autistic spectrum disorders (ASD), dyslexia and dyspraxia
- learning disabilities
- mental health conditions with symptoms such as anxiety, low mood, panic attacks, phobias, or unshared perceptions; eating disorders; bipolar affective disorders; obsessive compulsive disorders; personality disorders; post-traumatic stress disorder, and some self-harming behaviour
- mental illnesses, such as depression and schizophrenia
- produced by injury to the body, including to the brain

The act states that a person who has cancer, HIV infection or multiple sclerosis (MS) is a disabled person. This means that the person is protected by the act effectively from the point of diagnosis.

B12 The act provides that, where an impairment is subject to treatment or correction, the impairment is to be treated as having a substantial adverse effect if, but for the treatment or correction, the impairment is likely to have that effect. In this context, 'likely' should be interpreted as meaning 'could well happen'. The practical effect of this provision is that the impairment should be treated as having the effect that it would have without the measures in question (Sch1, Para 5(1)). The act states that the treatment or correction measures which are to be disregarded for these purposes include, in particular, medical treatment and the use of a prosthesis or other aid (Sch1, Para 5(2)). In this context, medical treatments would include treatments such as counselling, the need to follow a particular diet, and therapies, in addition to treatments with drugs. (See also paragraphs B7 and B16.)

B13. This provision applies even if the measures result in the effects being completely under control or not at all apparent. Where treatment is continuing it may be having the effect of masking or ameliorating a disability so that it does not have a substantial adverse effect. If the final outcome of such treatment cannot be determined, or if it is known that removal of the medical treatment would result in either a relapse or a worsened condition, it would be reasonable to disregard the medical treatment in accordance with paragraph 5 of Schedule 1.

B14. For example, if a person with a hearing impairment wears a hearing aid the question as to whether his or her impairment has a substantial adverse effect is to be decided by reference to what the hearing level would be without the hearing aid. Similarly, in the case of someone with diabetes which is being controlled by medication or diet should be decided by reference to what the effects of the condition would be if he or she were not taking that medication or following the required diet.

B18 Progressive conditions, which are conditions that have effects which increase in severity over time, are subject to the special provisions set out in Sch1, Para 8. These provisions provide that a person with a progressive condition is to be regarded as having an impairment which has a substantial adverse effect on his or her ability to carry out normal day-to-day activities before it actually has that effect.

B19. A person who has a progressive condition, will be treated as having an impairment which has a substantial adverse effect from the moment any impairment resulting from that condition first has some adverse effect on his or her ability to carry out normal day-to-day activities, provided that in the future the adverse effect is likely to become substantial. Medical prognosis of the likely impact of the condition will be the normal route to establishing protection under this provision. The effect need not be continuous and need not be substantial. (See also paragraphs C5 to C8 on recurring or fluctuating effects). The person will still need to show that the impairment meets the long-term condition of the definition. (Sch1, Para 2)



B20. Examples of progressive conditions to which the special provisions apply include systemic lupus erythematosus (SLE), various types of dementia, and motor neurone disease. This list, however, is not exhaustive.

B21. The act provides for a person with one of the progressive conditions of cancer, HIV and multiple sclerosis to be a disabled person from the point at which they have that condition, so effectively from diagnosis.

Section E: Disabled children

E1. The effects of impairments may not be apparent in babies and young children because they are too young to have developed the ability to carry out activities that are normal for older children and adults. Regulations provide that an impairment to a child under six years old is to be treated as having a substantial and long-term adverse effect on the ability of that child to carry out normal day-to-day activities where it would normally have a substantial and long-term adverse effect on the ability of a person aged six years or over to carry out normal day-to-day activities.

E2. Children aged six and older are subject to the normal requirements of the definition. That is, that they must have an impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities. However, in considering the ability of a child aged six or over to carry out a normal day-to-day activity, it is necessary to take account of the level of achievement which would be normal for a person of a similar age.

E3. Part 6 of the act provides protection for disabled pupils and students by preventing discrimination against them at school or in post-16 education because of, or for a reason related to, their disability. A pupil or student must satisfy the definition of disability as described in this guidance in order to be protected by Part 6 of the act. The duties for schools in the act, including the duty for schools to make reasonable adjustments for disabled children, are designed to dovetail with duties under the Special Educational Needs (SEN) framework which are based on a separate definition of special educational needs. Further information on these duties can be found in the SEN Code of Practice and the Equality and Human Rights Commission's Codes of Practice for Education.

Case study: Lucy's story



Lucy became ill at the age of 14 and was diagnosed with Ehlers-Danlos Syndrome, or EDS, a few days after her 15th birthday. Lucy's condition is genetic and it has no cure. Lucy describes her experience of education while living with a life-limiting condition.

“Though I appreciate not everyone is enthusiastic about their schooling, education is extremely important to me. I love learning and was aiming for a career in medicine, even when disabled, but I became too unwell. I still favour a textbook over a novel any day! My senior school was extremely unsupportive when I became ill in 2008 aged 14. We had to fight for me to continue my education – despite it being compulsory to the age of 16 (now 18). My mum arranged meetings with the school Special Needs co-ordinator and made several journeys to school each week to collect work for me which never materialised. Eventually the Children's Support Services (CSS) – who we had to contact ourselves as my school wouldn't – stepped in and provided the very best education in the allocated six hours per week I was allowed. Without them I would not have received any tuition. I was desperate to learn, but was being penalised because I was sick. Had I been expelled there is a very detailed process the school would have been legally bound to follow immediately to provide me with tutoring through Children's Support Services, but I missed a whole term of Year 9 because my school couldn't – or wouldn't – fill out the necessary forms. Fortunately with the help of the excellent CSS tutors I completed my GCSEs in 2010 at the same time as my former peers. I achieved an A*, three As, two Bs, one C and two Distinctions. It took a lot of hard work on my part, but as I said, I love learning.

Friendships through the teenage years are complicated enough. Hormonal changes, the opposite sex, fitting in, being the 'same' as your peers, having the right clothes, the right accessories, the right body image. If you throw being ill into that mix and not attending school – friendships become an impossibility. I lost all but one of my friends. Losing my school friends hurt me the most. They were supposed to be my friends, but now I wasn't worthy of their friendship. I think, had my senior school allowed me to come in for social times, not necessarily focused on lessons alone, it could have made a big difference to my relationships with my friends. Once I was unable to go to school, it was like I didn't exist at all. Put it this way – I only got one letter after I became ill, and that was a letter inviting me on a school skiing trip. I only appeared in our yearbook once, and it was my school photo from Year 9 – they hadn't even bothered to ask for an up-to-date photo – and nobody signed my yearbook. I didn't appear in the film of everyone in my year. I just didn't exist, and I think this pushed my friends and I even further apart.”

Unsurprisingly, I favoured a new start in sixth form rather than staying at my school. I chose a college called SEEVIC close to my home and it was the best decision I've ever made. At the beginning of Year 11 we contacted the college. The staff could not have been more welcoming and supportive. We had meetings with the Learning Support/Special Needs co-ordinator, a tour of the college, I met some of the tutors, we were introduced to the college nurse and I was assigned a Learning Support tutor to help me with anything I needed. My timetable was arranged to suit my needs – I was studying Biology, Chemistry and Applied Science at A Level – and a copy of my support plan was

given to each of my tutors. Everything I needed was put in place, with a scribe in every lesson of mine to write for me, to make notes when I was unable to attend and to help me with practicals and experiments. They also provided an experienced tutor to come to my home for an hour once a week to help me with any work I may have missed or just for any additional help I required. Unfortunately I became too unwell after two terms to continue with my education, but my time at college was a pleasure thanks to their commitment to providing all their students with the best education and supporting them to reach their potential.

